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ABSTRACT

This book provides practitioners working with young adults with disabilities practical strategies for building expanded partnerships with parents during the transition years. It relies on three beliefs: parents need to be fully informed partners; practitioners need to empower parents to become partners; and parents can become accountable for actions upon and within the system. Chapters address the roles parents can and should play during the transition years, both in school and in adult service agencies. Chapters include: (1) "Introduction to the Role of Parents in Secondary Transition" (Amy M. Pleet and Donna Wandry); (2) "Defining the Family: Changing Demographics" (Vicki A. McGinley); (3) "Parents as Collaborators: Building Partnerships with School-Based and Community-Based Providers" (Sharon H. deFur); (4) "Parents as Evaluators and Decision-Makers" (Kris Schoeller and Ellie Emanuel); (5) "Parents as Trainers, Role Models, and Mentors" (Sharon M. Kolb); (6) "Parents as Instructors" (David F. Bateman and others); (7) "Parents as Systems Change Agents during Transition" (Mary E. Morningstar and Josie Torrez); and (8) "Next Steps" (Donna Wandry and others). The chapters develop, within each role, a vision of effective parent activities, success indicators, the challenges faced by parents, and practitioner strategies to empower parents. (Chapters include references.) (CR)

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A Practitioner's Guide to Involving Families in Secondary Transition

Donna Wandry

Amy Pleet

2003

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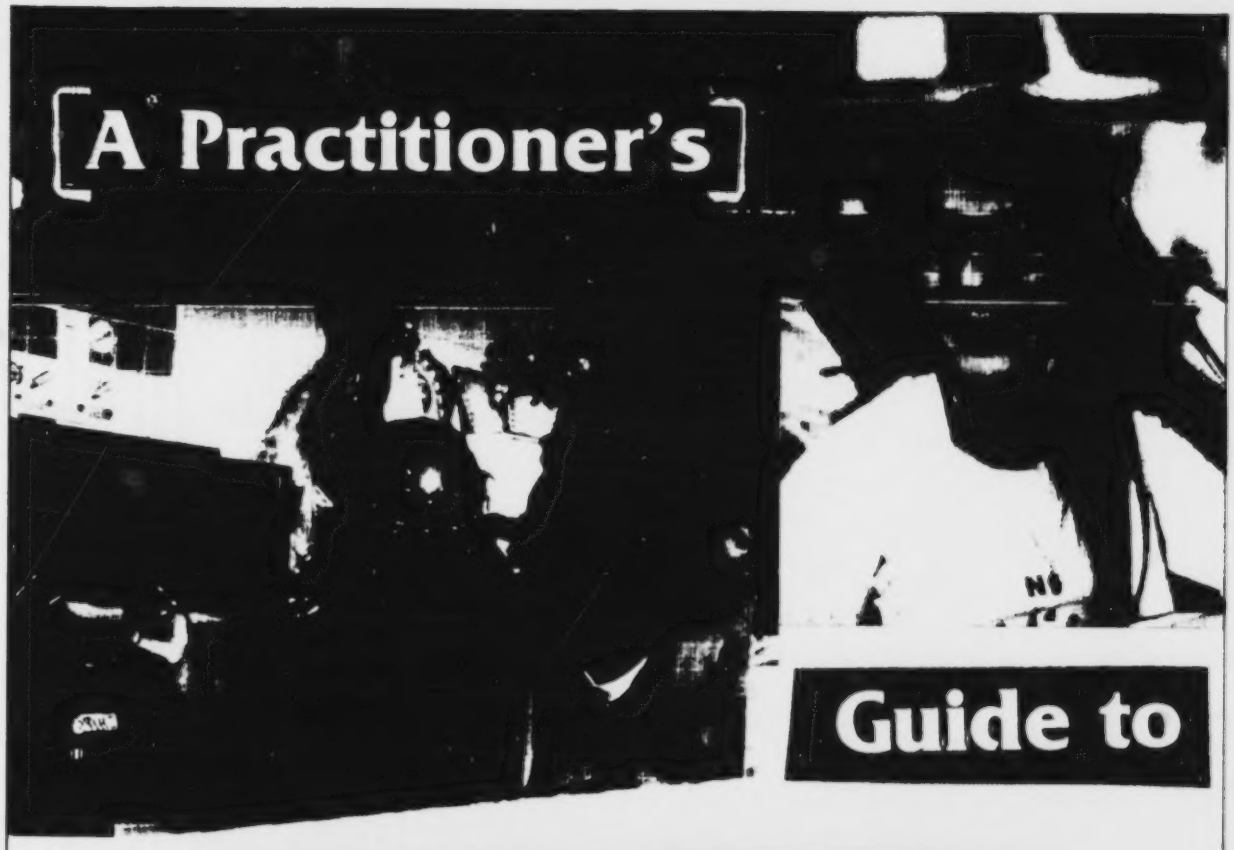

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Donna Wandry and Amy Pleet, Editors

Council for Exceptional Children

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Introduction to the Role of Parents in Secondary Transition

Amy M. Pleet and Donna Wandry

Context of This Monograph

Change is constant in education and in adult service provision. Fads and gimmicks come and go, many without any substantial research base. This book is devoted to a new movement that has been a long time coming and is not likely to pass. This topic bears serious consideration by educators and service providers: building partnerships with parents of their students and clients. Research (Epstein, 1995; National PTA, 1997) indicates that the ultimate success of these practitioners depends on their ability to build partnerships with parents of youth with disabilities in new ways. The purpose of this book is to provide to practitioners, working with young adults with disabilities, information and practical strategies that will support them as they build expanded partnerships with parents during the transition years.

Key definitions

First, let us define three key terms: parent, family, and partnership. In this publication, parent is intended in a broader sense than biological parents. We use the National PTA's definition of parents: "the adults who play an important role in a child's family life, since other adults-grandparents, aunts, uncles, step-parents, guardians-may carry the primary responsibility for a child's education, development, and well-being" (National PTA, 1997, p. 5)

Webster defines family as "a group of individuals living under one roof and usually under one head," and partnership as "a relationship resembling a legal partnership and usually

involving close cooperation between parties having specified and joint rights and responsibilities." Within a practitioner-family partnership, there are a number of joint responsibilities as all parties cooperate in supporting the young adult with disabilities to make a successful transition into adult life. There also are specified responsibilities-some assumed by the school or adult service agency and others assumed by the families. The specifics of the partnership will vary with the individual's disability, goals, and family circumstances.

Context

We are living in the midst of a paradigm shift in the service industry regarding accountability. Educators and adult service providers historically provided services to students or clients with their accountability measures focused on whether or not the services were provided. For example, they reported the number of speech therapy sessions a particular child had or the number of young adults who completed a vocational assessment. In the new paradigm, evaluative measures focus on the outcomes, or the results produced by these services. Practitioners must now document the extent of a child's growth, the number of evaluated youth who entered a career training program, or customer satisfaction within the evaluation. This shift in context has produced myriad changes in practices within the educational and adult service systems.

The Outcomes Movement

Government Performance and Results Act

In 1993, President Clinton signed into law the Government Performance and Results Act (GPRA, PL 103-62). This act required all organizations that received federal funding to establish performance measures and then track and report their results.

Each agency was required to a) set program goals; b) measure performance against those goals; c) report progress publicly; d) improve program effectiveness and accountability by promoting a new focus on results, service quality, and customer satisfaction; and e) improve service delivery by planning for meeting program objectives and providing information about program results and service quality.

The passage of GPRA was not a surprise. For some time, political and lobbying groups had publicized misuse of public funds and called for accountability measures. Nonetheless, organizations and agencies suddenly found themselves debating what their outcomes ulti-

mately were and grappling with how to measure them. For airports, the discussion centered not on how many planes took off, but on how many took off on time, how many accidents occurred, and how many pieces of luggage were lost and found. For the post office, the discussion shifted from how many pieces of mail were processed to how many pieces were misdirected and how long customers had to stand in line for service. The context shifted from routine operations to a focus on customer satisfaction and met needs.

The United States Department of Education shifted from a focus on whether the teachers had delivered the curriculum to whether the students were gaining in knowledge and skills. The Department announced four goals to meet the GPRA requirements regarding accountability:

1. Help all students reach challenging academic standards so that they are prepared for responsible citizenship, further learning, and productive employment.
2. Build a solid foundation for learning for all children.
3. Ensure access to post-secondary education and lifelong learning.
4. Make the United States Department of Education a high-performance organization by focusing on results, service quality, and customer satisfaction.

These four goals established a model for states and local school systems as they shifted to a focus on outcomes designed to address the challenge of GPRA.

Individuals with Disabilities Education Act

During this same time period, congressional leaders were engaged in hearings on the reauthorization of the Individuals with Disabilities Education Act (IDEA) of 1990 (PL 101-476). When IDEA of 1997 (PL 105-17) was signed, state and local special educational programs were required to conduct a comprehensive self-evaluation process. With specific criteria to address, each Local Educational Agency (LEA) assembled stakeholder groups to identify outcomes and outcome measures. Then the groups designed and implemented a self-evaluation process. No longer would it be sufficient to have the students' special education folders ready when the U.S. Office of Special Education Programs (OSEP) came for scheduled monitoring visits. Of course, the monitors would still be concerned with whether due process measures had been met and documented, but now the monitors would also be looking for documentation that student outcomes were improving. Data were gathered related to graduation rate, participation in general education programs, and performance on state and district level progress measures. Many states began follow-up or longitudinal studies of post-school outcomes of students with disabilities. Each LEA began to gather input from stakeholder groups with strong participation of parents. The Special Education Advisory Board, required to have 50% parents or individuals with disabilities as members, became influential. Parents shared their stories in interview, survey, and testimony. Their broad awareness of the whole lives

of their children affected special education leaders' decisions. The question shifted from "Are we following regulations in providing services?" to "Are we providing required services in ways that provide optimum student benefit?"

Foundations of Parent/Family Involvement

Epstein's Research on Parent Involvement in Education

For more than two decades, Joyce Epstein, director of the Center on School, Family, and Community Partnerships at Johns Hopkins University, has been leading research on types, outcomes, and methods of promoting parent involvement in education. Her early research into the effectiveness of school programs, the extent of family influence, and the impact of socioeconomic community conditions on the success of students revealed that these three forces could not be clearly distinguished (Epstein, 1996). She proposed that school, communities, and families have overlapping spheres of influence on children. Further, she advocated that the three entities form partnerships, mutually responsible for creating better programs and opportunities for students. These partnerships must view the child as a whole being, needing the influence of all three spheres in order to "engage, guide, energize, and motivate students to produce their own successes" (Epstein, 1995, p. 702).

Regarding the evolution of the parent-involvement movement, Epstein states, "The first frameworks focused mainly on the roles that parents needed to play and not the work that schools needed to conduct in order to organize strong programs to involve all families in their children's education" (Epstein, 1996, p. 211). This description aptly fits the evolution of parent involvement in transition planning. The special education research conducted over the last 10 years has focused on what the parents were and were not doing, rather than on what the schools were doing to promote parent partnerships.

Epstein reported that the underlying research question in general education has moved from, "Are families important for student success in school?" to "If families are important for children's development and school success, how can schools help all families conduct the activities that will benefit their children?" (Epstein, 1996, p. 213). The research of the National Center on Families, Communities, Schools and Children's Learning, created in 1990 by the federal government at Johns Hopkins University under Epstein's leadership, included more than 20 researchers from several disciplines. Using varied methods and measurement models, they worked closely with educators and parents to design and study new approaches for productive partnerships (Epstein, 1996). The National Center created an International Network of more than 300 researchers in the United States and more than 40 nations "to encourage and to share

work on many topics related to school, family, and community partnerships" (Epstein, 1996, p. 212). Through this collaborative venture, studies "began to clarify the amorphous term 'parent involvement,' and recast the emphasis from parent involvement (left up to the parent)...to school, family, and community partnerships...The concept of 'shared responsibility' removed part of the burden from parents to figure out on their own how to become or stay involved in their children's education from year to year and put part of that burden on schools to create programs to inform and involve all families" (Epstein, 1996, p. 211). The result of this research has led to the shifting paradigm for parent involvement in education.

Transition Implications of Epstein's Research

Research findings from the National Center have implications for increasing transition outcomes for students with disabilities. First, the research has shown that partnerships contribute to increased student achievement. Ultimately, collaborating with parents should contribute to enhanced post-school outcomes. Second, the research confirms that parent involvement tends to decline across the grades, unless schools and teachers work to develop and implement appropriate practices of partnerships at each grade. Parents will continue to be involved with their children's educational and occupational programs, if practitioners create appropriate supports. Third, the research indicates that teachers' practices to involve families are at least as important as family background variables such as race or ethnicity, social class, marital status, or mother's work status for determining whether and how parents become involved in their children's education. That is, schools and teachers who practice strategies for building parent partnerships can have more influence on parents' involvement than family background variables. Fourth, the research has documented that there are subject-specific links between the involvement of families and increases in student achievement. For example, studies of teacher practices to involve parents with in-home reading activities report more involvement in family reading and improved student reading scores. Fifth, not all activities to involve families lead quickly or directly to increased student outcomes. Instead, for example, interactions about parenting skills during transition years would first be expected to affect parents' informal interactions with their young adults. If families continue to influence or reinforce students' attitudes, behaviors, and motivation, then student outcomes may increase over time. And sixth, the research has shown that all parties want more partnerships between schools, families, and communities, but most do not know how (Epstein, 1995, 1996; Pleet, 2000).

The Epstein Six Types of Involvement resulted from this extensive research, providing a useful framework for developing partnerships with families. Each type is discussed here with applications for transition planning (Pleet, 2000).

1. Parenting activities are conducted to equip parents with the information, skills, and supports to be effective parents to their children with disabilities. During the transition years, questions that will be addressed include: What do I need to know as a par-

ent about the adult service eligibility system so that I can assure that my teenager will be able to access needed supports and services? How do we provide guidance to our teenagers as they make choices about future employment, further education, and independent living? How do we coach our teenagers as they develop self-determination skills needed for the future?

2. Communicating activities must be reciprocal, regular and meaningful. Schools and adult providers will inform parents about upcoming events and proposed program or system reforms. Schools will provide opportunities for input from parents and interagency organizations. The public forums required under IDEA (1997) and the Rehabilitation Act (1998) are examples of communication activities. Most importantly, schools will establish reciprocal channels of communication about each individual student's issues, goals, and progress.

3. Volunteering activities include opportunities for parents to support school goals and students' learning "in any way, at any place, and at any time-not just during the school day and at the school building" (Epstein, 1996, p. 705). Parents may contact their own employers to arrange for job shadowing or field trip opportunities for students. They may organize a parent support network with other parents of transition-aged youth. Parents may volunteer to serve on an advisory board. The important role of the school is to (a) recruit parent volunteers, (b) provide for schedule flexibility, (c) address training needs, (d) match parents' talents with school and students' needs, and (e) recognize the parents' efforts. The view of volunteering presented here is quite different from the old paradigm of parents volunteering at a bake sale.

4. Learning at home activities are designed to engage parents as partners in student learning outside of the school or adult training facility. One activity that has yielded positive results for students and for schools is to expand homework to include interactive assignments for students to complete with family members. For example, homework might be to interview two working adults in a student's home or community about the process that led to their career choices. Schools also provide guidance to parents as to the expectations for their roles in homework, i.e., "encouraging, listening, reacting, praising, guiding, monitoring, and discussing—not teaching" (Epstein, 1995, p. 705).

5. Decision making activities include parents in school decisions and develop parent leaders and representatives. The increased requirements with IDEA (1997) call for special education advisory panels consisting of more than 50% parents or individuals with disabilities. The challenge for schools will be to promote participatory opportunities for all parents of students receiving special education services. Schools need to create multiple strategies to get parents involved in developing and evaluating special education programs and services, in support of parents' evolving roles as evaluators and change agents of transition practices.

6. Collaborating with community activities have significant importance for families. During the transition years, consideration of work-based learning opportunities, community-based learning opportunities, and linkage with community and adult services is a required component of transition planning for each student, beginning no later than age 14, who receives special education services. The challenge in this type of parent involvement is to develop strategies that empower the students, integrate resources, and yet keep the parent involved. One way to collaborate with the community would be to produce a transition fair with adult and college support services and employers. Additionally, parents and students could take an organized field trip to the local community college for an orientation about services, course expectations, and financial aid.

Schools that use the Epstein Typology framework can plan activities to incorporate several types of involvement. For example, if a school or adult agency sponsors a parent-to-parent mentoring program, organized by the parents, this activity could fit involvement as types 1, 2, and 3. The Epstein research is the basis for the National Standards for Parent/Family Involvement Programs (National PTA, 1997), as well as a primary foundation for the conceptual framework for this monograph.

The Changing Role of Parents as Partners

Parent Role Changes Across Education

As a result of the research of Epstein and others, a paradigm shift is occurring across education related to parent involvement. Historically parents were viewed as school volunteers, who were primarily responsible for ensuring that their children came to school ready to learn. With the publication of Goals 2000, came the charge, "By the year 2000, every school will promote partnerships that will increase parents' involvement and participation in promoting the social, emotional, and academic growth of children."

As many school leaders developed partnership plans, they realized that partners come with complementary but different levels of expertise, skills, and knowledge. Yet, they come together with a common vision and goals. Planners recognized that partnerships must be built on open communication, trust, and flexibility and must focus on collaborative problem solving and strategy design. Educational leaders began to design new approaches to offer parents opportunities. Schools welcomed parents into efforts to meet the national goals to "Help all students reach challenging academic standards so that they are prepared for responsible citizenship, further learning, and productive employment" (GPRA, 1993). Many school leaders acknowledged that partnership with parents was critical.

Unfortunately, there were also school leaders who resisted building partnerships with parents. Their roles as the "experts" in educational matters were threatened as they confronted the new paradigm. These educators enjoyed the superiority of having the answers at the back of the book. They thought they might lose control of their classrooms if they used different teaching styles to address interactive or differentiated learning strategies. They were afraid of what would happen if they included parents on school reform committees as equal partners. They held parents at arms' length, giving them only the most basic of information without revealing the deep-seated issues underlying school-reform dilemmas.

I feel that lack of knowledge of the transition process is the greatest barrier to building successful partnerships. I believe all parents are concerned about their children's futures, yet many feel unqualified to contribute to the process. (Chris Cape, Special Education Teacher)

Parents either became silent, acquiescing members or became aggressive in their determination to make themselves heard (Garriott, Wandry, & Snyder, 2000). Many parents spoke at school board meetings, wrote letters to newspapers, and refused to accept inadequate education for their children. Some educational leaders took deliberate measures to reduce the impact of these parents. Administrators discouraged teachers from leaking information to parents. More than one principal has refused to allow teachers to conduct parent information nights because they perceive that an armed parent is a dangerous parent. Don Davies (2002) conducted research to compare the practices he observed in 1996 with current practices of involving parents as partners in education. He noted a change in partnership language; politicians, educational leaders, advocates, and conferences all highlight family involvement and partnership. On the other hand, he found that practices in most schools have hardly caught up with the flourishing rhetoric (p. 389). Davies recommends that teachers and principals join together to design the partnership approaches to be used.

Parent Role Changes in Special Education

Parent involvement in special education began with the Education of the Handicapped Act (PL 94-142, 1975). Schools were mandated to involve parents in the identification, assessment, and individualized program decisions for their children with disabilities. This process required parental consent, but did not promote partnerships. GPRA and Goals 2000 influenced legislators developing the reauthorization of IDEA 1997, which clearly directed state and local educational agencies to build partnerships with parents.

IDEA 1997 enhanced requirements for building partnerships with parents can be grouped into five categories:

1. States must ensure that parents' rights are protected and complaint procedures and safeguard procedures for each child's Individualized Education Programs (IEP) are disseminated and implemented. IDEA 1997 requires schools to document attempts to get parents to participate in their child's IEP planning meetings.

2. A majority of the State Advisory Board must be individuals with disabilities or parents of children with disabilities. The Board advises state or local special education office on the unmet needs of students with disabilities. Board Members comment publicly on proposed rules and regulations and advise the state on how to develop evaluative measures and report the data to the U.S. Office of Special Education Programs. The Board also advises the state on developing or implementing policies that coordinate services for students with disabilities. Finally, the State Advisory Board conducts public meetings and submits an annual report to the state.

3. Parents are integral to the state and local improvement plans. IDEA mandates that both plans include provisions for joint training of parents, special educators, related service providers, and general education personnel.

4. Parent counseling and training is now available as a related service on a child's IEP. This service is defined as "assisting parents in understanding the special needs of their child, providing parents with information about child development, and helping parents to acquire the necessary skills to allow them to support the implementation of their child's IEP."

5. Parents' feedback must be used to monitor local school systems and student placement. Information can be gleaned from questionnaires or in other ways to reveal parent perspectives on the effectiveness of special education services and programs for their children. Special education leaders must show how parent input was obtained and used in evaluation and improvement plans.

A Brief History of Transition Planning and the Parents' Role

Evolution of Transition Planning Requirements in IDEA

In 1984, Madeleine Will, assistant secretary of the U.S. Department of Education Office of Special Education and Rehabilitation Services, and a parent of a child with a disability, issued

a policy paper, "Bridges from School to Working Life." She spoke of services needed to help students with disabilities make the transition from secondary education to adult life. She encouraged schools and adult service agencies to address the complex issues that students and families face as they make this transition. IDEA of 1990 required schools to include transition planning in addition to the IEP. General practice involved two meetings. First, IEP teams discussed students' performance levels and then developed annual goals and objectives. At separate meetings, they discussed the students' future, post-school plans and developed the Individualized Transition Plan. Parents were encouraged to attend these additional sessions that often had little relationship with the IEP goals and objectives.

The reauthorization of IDEA 1997 shifted the focus for transition planning. The purpose of special education was now designed to "provide a free appropriate public education designed to meet student's unique needs and *prepare them for employment and independent living.*" This shift in focus caused transition to become part of the initial process. In other words, once the student reached 14 (or earlier, if appropriate), the IEP team would establish the student's interests and future goals as a context for the student's individualized planning process. The team would then examine the student's present levels of performance, transition service needs in a course of study, and transition services needed in a coordinated set of activities after which the team would develop the annual goals and objectives (Storms, O'Leary, & Williams, 2000). Teams began to realize how crucial parent input was to this new process. Parents made important contributions to discussions about their children's hopes, dreams, present performance, and goals. (Parents and guardians often become the case managers for young adults with disabilities.) Parents helped their children to clarify post-school goals and articulate needs and preferences (McDonnell, Mathot-Buckner, & Ferguson, 1996, p. 93).

Educators and parents discovered that preparing students to assume responsibility for themselves increased their motivation, ownership of the educational process, and improved their outcomes. In addition, students learned essential skills for gaining services and accommodations in adult settings (colleges, work sites, and adult agencies).

The greatest barrier I feel parents face is that for 18-22 years the parents deal with the public schools, and feel very comfortable in that situation. Then they have to learn a new system, which can be very confusing to them; sometimes the system can run over them.
William J. Schmidt, Director of Day Program Services) [AZ]

Rehabilitation Act Requirements

The 1998 reauthorization of the Rehabilitation Act incorporated requirements for reporting outcomes and for building parent partnerships. The passage of the Rehabilitation Act Amendments of 1998, as a component of the larger Workforce Investment Partnership Act (PL 105-22), reinforced the 1993 regulations that encouraged client and family involvement. In addition, several changes in the 1998 amendments supported the partnership message.

The Workforce Investment Partnership Act (WIPA) established youth councils within local Workforce Investment Boards (Section 117, Title I) which demonstrated a strong commitment to client input. The Act also required the Rehabilitation Services Administration to become a partner in the one-stop service delivery system mandated by WIPA (Section 121). This practice, simplifies client access to employment-related adult service agency information. This, in turn, should positively effect the ability of agencies and clients to work together in expediting the application and eligibility-determination process.

The Rehabilitation Act of 1993, and the 1998 Amendments, have several components that potentially strengthen the partnerships between agency providers, clients and their families. Specifically, a youth in transition who is an applicant or eligible client of Rehabilitation Services Administration, and who is developing on Individual Plan for Employment (IPE), is provided (a) information on increased options and (b) technical assistance in developing the IPE as well as other pertinent information. The Act calls for clients to make "informed choices". Although the regulatory language (Section 361.52) is not defined, the intent is to increase empowerment of those accessing rehabilitation services and the agency's responsibility to provide adequate information to support informed choices.

Systemically, the Rehabilitation Act and its amendments offer regulatory language that strengthens the voice of the clients and their families. Within the due-process arena, the acts and amendments are clear in their intent to provide effective mediation and impartial hearing rights for applicants or eligible individuals and their representatives (Section 361.57) who may be dissatisfied with planned or provided services. Representation within systemic structures also has increased—State Rehabilitation Councils must include a representative from a parent training and information center. This presence is particularly important, since the Council, in consultation with the Workforce Investment Board, is empowered to evaluate and change the system.

Finally, the Rehabilitation Act and its Amendments offer direct service to families of applicants and eligible individuals, in recognition of the potential for family involvement in the rehabilitation process. Specifically, vocational rehabilitation services are available, as necessary, to family members to enable the client to achieve an employment outcome. This family partnership also is a basis for the provision of training and technical assistance in the use of assistive technology, since the family's support may be necessary to develop the client's proficiency across settings.

The language and the intent of the Workforce Investment Partnership Act and the Rehabilitation Act and its amendments appear to have strong roots in empowerment. The challenge will be to translate the language and intent into practices that truly embrace these partnerships.

Conceptual Framework

The conceptual framework for this book is built upon three beliefs:

- Parents need to be fully informed partners in education and adult services.
- Practitioner's need to empower parents to become partners.
- Parents can become accountable for action upon and within the system.

The authors address family systems, structures, and sociological context (chapter two), and the roles parents can and should play during the transition years, both in school and in adult service agencies (chapters three to seven). These roles are:

1. Parents as collaborators
2. Parents as decision makers and evaluators
3. Parents as role models, trainers, and mentors
4. Parents as instructors
5. Parents as systems change agents

The chapters develop, within each role, a vision of effective parent activities, success indicators, the challenges faced by parents, and practitioner strategies to empower parents.

Charge to the Reader

We challenge you, our readers, to empower families to emerge from the transition process, as full partners. Your attitude and actions will speak louder than your words. When parents reflect on their contact with you, what will they say? Will they say you gave them the knowledge and skills to become collaborators, decision-makers, evaluators, role models, trainers, mentors, instructors, and system change agents? Will they say you supported their efforts to become more effective parents and influential members of the community? Will they say you made a difference in their family's partnership with professionals? We hope this book will give you useful tools. We know every tool will not produce the same results with every family. We trust you to use your professional judgment and creativity to design strategies that

work and share your successes and lessons learned with your colleagues. Together we can build strong partnerships with parents that will improve the lives of young adults with disabilities.

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2

Defining the Family: Changing Demographics

Vicki A. McGinley

Changing family structures and increasing ethnic/cultural/racial diversity has expanded the complexity of service provision since the passage of PL 94-142, the Education for All Handicapped Children Act (1975), which required schools to include parents in educational planning for students with disabilities. Diverse family structures and ethnic perspectives impact the work of school and adult service professionals as they work with a wide range of families to build partnerships during the transition and implementation process. This chapter provides strategies for building those partnerships.

Family Structures

What is family? Webster defines family as (a) "a group of individuals living under one roof and usually under one head" and (b) "the basic unit in society traditionally consisting of two parents rearing their own or adopted children; also: any of various social units differing from but regarded as equivalent to the traditional family." These definitions reflect changing views of what a family is. Sociological research has studied the configurations of families, reporting diverse family models as well as many differing responses to parenting a child with disabilities. The predominately two-parent family has been replaced by other structures including extended, foster, nuclear, same-sex, single, and step-parent models. With each of these models comes a different set of challenges related to child-rearing, family function, and the interaction between the family and the school or adult agency. Patton, Cronin and Jairrels (1997) state that the transition process is affected by the changing family structure and diversity in this country.

Understanding Family Challenges

Practitioners need to exhibit sensitivity to the issues families face on a daily basis. While family differ, all families face some of the same challenges:

1. *Stresses of juggling family and work life.* This may inhibit parenting, individual and couple time, resulting in problems of communication, socialization, and overall well-being of family members. The United States is known for long work hours and limited vacation and family leave time. The stress of having a family and working outside of the home may take its toll on how well the family functions. For example, homework may not be completed if parents work late hours and children are spending time at home alone or in other childcare arrangements. This will be less of a problem for a nuclear family where the mother stays home. However, this type of family is the minority. According to the AFL-CIO (2002), more women are working outside the home than ever before. Two-thirds of women with children younger than six and more than three-fourths of women with school-age kids work outside the home.

2. *Conflicts due to missed work time for school meetings.* Employers often become exasperated when parents have to leave work for childcare responsibilities.

3. *Stresses from poverty, such as poor housing conditions and nutrition.* One in four children live in poverty (Lewit, Terman, & Behrman, 1997), which alienates the family from the educational system, as daily survival becomes the family's primary goal. Poor living conditions, as a result of prejudice and poverty, continue to affect a disproportionate number of African Americans. Major inequities still exist in income, health, and quality of life between African Americans and Anglo Americans, leaving many families at risk for poor housing, overcrowding, crime, lack of services, high infant mortality, and poor health.

4. *Issues related to having children with serious behavioral and/or medical concerns.* Parents report that time and energy devoted to a child with serious concerns frequently eclipses "normal" family life. In addition to usual parental duties, they spend inordinate amounts of time with specialist appointments and find it difficult to arrange for day care or respite care so that they can have breaks from their full-time child-care responsibilities. These parents have less energy to devote to educational and transition concerns and may experience a greater sense of burnout by the time their children reach adolescence (Brotherson, Berdine, & Sartini, 1993).

5. *Family structure models.* Stepfamilies and grandparents rearing children must deal with conflicts over family members' roles, issues of boundaries, and child rearing. Also, foster families may encounter children with behavioral issues caused by the previous foster-care placement(s) and subsequent move(s). Single-parent families have a higher rate of poverty and the parent, usually the mother, may have to work long

hours and rely on outside caregivers for her children. According to the U.S. Census Bureau (1998) there are 11.9 million single parents in the United States today and 28% of all children in the United States under the age of 18 live with one parent.

6. *Diversity challenges.* Speakers of English as a second language may be intimidated by meeting with education and adult service professionals. Also, some families' value systems may be at odds with the dominant educational value system. For example, according to Bennett (1989), the institutional and professional structure of the school may intimidate Hispanic parents so much that they will not participate in developing their children's IEPs. Thus, parent support and planning for the transition process, as part of the IEP development, may be difficult or nonexistent.

Family Diversity

Definition

Webster defines diversity as: (a) "differing from one another" and (b) "composed of distinct or unlike elements or qualities."

The demographics of the United States have been changing rapidly and will continue to change in the coming decades to reflect families with many different cultures, ethnicities, races, socioeconomic levels and native languages. It has been predicted that by mid 21st century, no single ethnic group will make up the majority of the United States population. Further, by 2025, half of the school population will be non-Anglo (U.S. Census Bureau, 2000).

According to Hanson (1992), culture is the framework that guides one's life. Families from the same cultural background may share tendencies, but will not behave in the same way. Many factors such as socioeconomic status, education, age, religion, and location of residence, cause these variables. Therefore individual families with or without disabilities will cope differently.

Deepening Cultural Sensitivity

Persons working with children, i.e., educators, counselors, therapists, and adult service providers, need a sense of how an individual family structure and diversity may affect school planning, particularly the transition from student to adult roles. According to Steinberg and Davila (1997), a family's culture and ethnicity influence their response to a disability.

Individuals from within these families may treat disability differently, depending on family structure, gender, acculturation and beliefs about health and disabilities.

According to Kalyanpur and Harry (1999), there are three levels of cultural awareness: overt, covert, and subtle. While all three awareness levels are important in developing reciprocal relationships with families, professionals who regularly employ subtle awareness may be more effective. Practitioners operating at the overt level note obvious external differences, such as manner of dress and language spoken. Their stereotyped misconceptions will affect interaction with the family, which are likely to limit the development of a partnership with that family.

Practitioners move to covert awareness when they observe individual differences a family exhibits, such as communication styles or responses that reflect their values about status. For instance, a practitioner may note that a family tends to remain silent during part of a planning meeting. A practitioner operating at the covert level of awareness will seek the family's explanation for this silence. To operate at the covert level, practitioners must have background knowledge about the specific cultural group. However, our knowledge about a cultural group tends to be stereotypic and is not always helpful. Acculturation levels of families vary greatly, affecting how closely they may conform to these expectations of behavior. However, practitioners who do not move beyond the covert level will not truly build meaningful partnerships with families.

A practitioner who reaches the subtle level of cultural awareness understands the beliefs and values that a family holds which may contrast with those of the education and service system. To achieve this subtle awareness, Kalyanpur and Harry advise practitioners to ask themselves "Why do I want 21-year-old Hussein to move out on his own into a group home?" (p. 117). By posing this question, practitioners begin to understand that the special education culture values independence and self-reliance. Hussein's family may value interdependence and might not agree that he should leave the family home, particularly since none of his nondisabled siblings did. Only by becoming aware of the values embedded within the system—and then openly seeking to understand the family's values—can subtle "cultural dissonance" be detected and addressed.

Explanations and examples relative to family structures and cultural differences are provided to empower practitioners to take the first steps toward cultural reciprocity with parents. Practitioners must be careful to avoid stereotyping and assumptions that all families with the same backgrounds will relate to them in the same way.

Building Partnerships with Diverse Families

Families cope with problems across their lifespans, but must address additional issues when children with disabilities enter adolescence. According to Turnbull and Turnbull (1977), the

time of adolescence and young adulthood places families in the most difficult transitional periods. Families face three specific challenges when children with disabilities enter these transition years:

1. Independence versus continued dependence on the family system
2. Issues related to entering the world of work; and
3. Sexuality issues.

During this time, school and adult service providers must help families work with adolescents to address issues such as sexuality/gender identity, career preparation, independent living skills, and residential options. For example, many families tend to be paternalistic. If the father has difficulty accepting disability, it may be the mother who interacts with the school (Rivera & Cespedes, 1983). However, practitioners need to be aware if the family operates in a paternalistic style, which could affect sexuality, career decisions, and the practioners' interaction style with the family.

(My parents) were very aware of my situation and made sure that I had the best services possible, while at the same time letting me be an advocate for myself in acquiring the services I needed. (Name withheld) [VA]

Decisions continually have to be made regarding which transition areas are most important, as well as when, where, and how training and support should be provided. The young adult's preferences must be assessed through these years and matched to the availability of employment, residential options, and social or leisure programs. Practitioners must teach the most important skills related to adult independence. At these transition points, school and family views may differ greatly. Families may be more concerned with socialization and less with moving their child into the world of work. For example, members of some cultures generally respond to disability by offering support and comfort in the home and community. However, this support can be excessive, interfering with the move towards independence for the person with a disability (Cruz, 1979). In other cultures, the extended family is a source of strength, and group effort for the common interest is taught as a strategy for survival (Billingsley, 1974). This is vastly different from the Euro-American culture, where the concept of family generally refers to immediate family members. Extended family may or may not live close by and may not participate actively in the nuclear family (Lynch & Hanson, 1992). Thus, the practitioner must consider the family's level and type of involvement, as well as the age of child with a disability.

Practitioners must help parents identify their expectations for the young adult. Since transition planning is about adult life, educators must fully explore parents' short-and long-term expectations to ensure their youth's participation in personal management activities and routines. In addition, practitioners must help parents identify the kinds of support that will be needed to reach their goals (Turnbull, Turnbull, Bronicki, Summers, Roerder-Gorder, 1989).

(My parents) help me. They understand me and what I can do. I am a good worker, but sometimes people don't trust me to do the right thing. It takes me longer. My parents know they can trust me.
(Brett Nelson, Student) [MN]

Challenges Diverse Families Face when Children with Disabilities Enter Adolescence

Some of the same challenges that became an issue for a family of an adolescent with disabilities during high school will continue into adulthood. These challenges may become more prevalent as siblings who once were a support leave home and parents age. Adult service providers are confronted with providing services to families that hold different belief systems about disability and therefore may need quite different services or approaches than the agency is accustomed to delivering. For example, researchers (Spector, 1985; Seligman & Darling, 1989) have found that some Hispanic populations interpret disability as divine punishment, and some within this group may seek the help of a folk healer. Some families with Native American roots may view the causes of disability as witchcraft, spirit loss, or actions taken that were taboo. Tribal ceremonies may be held to help the family and the child. Many families from African-American, Anglo, and other cultures may attribute disability to misfortune or parental problems (Willis, 1992). Among the various Asian ethnic groups, the most severe disabling conditions (e.g., those associated with developmental disabilities) are traditionally viewed with considerable stigma. The cause of the disability may be seen as the mother's presumed failure to follow dietary and health care regiments or her violation of some taboo. Illnesses may be attributed to external or internal forces such as excessive emotions of joy, anger, hate, jealousy, sorrow, worry, or fear (Chan, 1992). Attitudes toward disability may also be affected by religious beliefs. For example Asian Americans, who have been influenced by religious beliefs (such as Shamanism) may believe that the spirit must be worshipped and well served to prevent misfortune (i.e., disability) and to bring good fortune (Chan, 1992, and Mun 1979).

Knowing the families' belief system about the origin of disability may help the practitioner understand the decisions a family makes and will let the practitioner know what kind of supports they will need to work with the family.

Challenges include trying to change the perceptions and belief systems of the parents. They often confuse empowering the young adults with abandoning their parental responsibilities. (Sergio Fernandez, Vocational Rehabilitation District Program Representative) [AZ]

Adult service providers will also need to vary services for families that handle life stresses such as money, work, aging, and success differently. Kuehn and Imm-Thomas (1993) provide an example of these challenges. They report that Native Americans have a disproportionately high incidence of disability and high rates of unemployment. Native Americans therefore are in high need of adult services; however the traditional rehabilitation programs have been largely unsuccessful with this population. Martin, Frank, Minkler, and Johnson (1988) surveyed vocational rehabilitation counselors who worked with Native Americans. The counselors reported that sensitivity to culture, language, and community was the most effective approach to working with these families. Understanding different cultural groups' value system regarding the life issues mentioned above will help adult service providers work with families.

Some studies (Hodge & Edmonds, 1988; Joe, 1988) found that the remoteness of the family residence related to whether they referred their children for disability services. The problems faced by minorities with disabilities are exacerbated by the social inequities of having multiple minority status. This has been found with the Latino population in particular, as they have to cope with ethnic, racial, linguistic, and disability inequities (Arnold, 1983).

In addition, Baldwin and Smith (1984) reported that adult services, particularly in the United States, can be a very selective process. Only individuals identified as being "most likely to succeed" receive services, those persons with disabilities may be easier to work with. Thus, minorities with disabilities have an even greater hurdle to cross.

Using diverse people in training and meetings, providing services in the family's community and native language, and developing employment in the community is a successful formula for working with diverse families. In addition, practitioners need to develop a thorough understanding of cultural influences and sensitivity to the similarities and differences between themselves and the families they serve (Gladding, 1998).

Using Cultural Reciprocity to Build Partnerships with Diverse Families

Kalyanpur and Harry (1999) introduced the concept of cultural reciprocity as a framework to better understand other cultures. Their work promotes an awareness of the underlying system values as well as an understanding of family values, which can avoid stereotyping. They recommend a four-step process to build cultural reciprocity:

First, professionals will reflect on their own values and reactions and those of the organization they represent. This step is not as easy as it sounds; practitioners are so acclimated to the disability system values, that they may not recognize them until they encounter someone with a different orientation. Reflection should include values embedded in the professional interpretation of the student's difficulties, and the values underlying the recommendations for service.

Second, professionals will investigate the values of the family, beginning with the overt generalizations of people from that culture, but going beyond generalizations to discover the covert and subtle values of that individual family. Professionals must keep in mind that each family is unique and learn to what extent the family accepts the professionals' interpretation of the youth's disability and recommendations for programming and service.

Third, professionals will iterate the distinction between the two sets of values. Only by openly stating and respecting the differences can they be recognized and discussed. Professionals must explain the disability and set the tone for further discussion.

Fourth, professionals will work collaboratively with the family to come to a resolution that respects the values of all parties. Once there is understanding of the differences in values, alternative approaches to the youth's needs may be considered.

In summary, as practitioners plan to develop partnerships with families of youth with disabilities, they should consider the families' uniqueness and the strengths and challenges they bring to the transition planning process. They should work to understand each family's communication style, level of comfort with educational professionals, and the appropriate degree of involvement. Practitioners should respect the willingness and desire of individual families to have extended family or community members involved in the meetings. During IEP or adult planning meetings, practitioners should proceed at the appropriate pace and take the time to explain the process to the family. They can build cultural reciprocity by first identifying the values embedded in the disability system and then encouraging the family to share about their values and beliefs. Open discussion of differences can lead to partnerships that will develop flexible solutions all parties will own. Ultimately, youth with disabilities will be the ones to benefit from a united support network as they strive for successful adult outcomes.

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3

Parents as Collaborators: Building Partnerships With School-Based and Community-Based Providers

Sharon H. deFur

Parental involvement and parent-school-community partnerships receive wide acclaim for making a positive difference in the educational and transition outcomes for children with and without disabilities (Cawelti, 1999; Greene, 1996; McNair & Rusch, 1991; Halpern, Yovanoff, Doren, & Benz, 1995; Morningstar, Turnbull, & Turnbull, 1995; Sample, 1998). But, what should this partnership look like? How would we know it if we saw it? How do we create these partnerships? This chapter proposes strategies for building promising collaborative partnerships between families of youth with disabilities and school and community service providers. These partnerships have two primary purposes: (a) to improve transition services and outcomes for youth with disabilities and (b) to develop within each family the knowledge and skills needed for families to continue in an appropriate support role for their adult child with a disability.

Parents often leave educational programming to the educators. They don't realize that their opinions and concerns can help improve programs that are available. (Chris Cape, Special Education Teacher) [AZ]

Definition

The term partner usually evokes an image of a spouse, friend, business associate, or some type of support. By definition, partners

- Establish relationships—partners define the roles and responsibilities of the partnership; they hold themselves and one another accountable for carrying out responsibilities.
- Have a joint interest—partners hold a common vision and set clear goals.
- Play on the same side—partners communicate honestly and openly, sharing and seeking information; they learn from one another; they use one another's strengths and help compensate for one another's limitations.
- Engage in activities to achieve a common goal—partners share responsibilities and trust one another to carry out those activities.
- Reinforce one another—partners support one another's efforts; they fill in for one another as appropriate for the skills of each.
- Share a common vocabulary or language that promotes understanding of their joint interest—partners use jargon-free speech.
- Share power and decision-making—partners recognize one another's perspectives and opinions as valid and consider them in making decisions.
- Share successes—partners credit the partnership as well as themselves.
- Share risks—partners believe that no one person is to blame when failures occur.
- Solve problems jointly—partners engage in active problem-solving together.

Clearly, to "partner" requires two-way participation; all parties in the partnership behave as partners. Partnering or the act of establishing partnerships, would be something that occurs together with families, not something done to, or for, families. Service providers can create an environment open to the formation of collaborative partnerships. This begins with a commitment to behaving as a partner consistent with the above description.

The greatest challenge (in building partnerships) is getting parents who are most in need of information to attend any meetings or workshops. (Karlton Ballard, Coordinator of Transition Services) [FL]

Developing Collaborative Transition Partnerships

Partnerships must be developed intentionally. Although youth and young adults with disabilities, and their families have participated in the special education system for many years, there is no guarantee that this participation has resulted in a partnership between families and the disability service system. Families and service providers report that the individualized education program (IEP) process, with a focus on school, has not consistently resulted in family-school partnerships (deFur, Todd-Allen, & Getzel, 2001; Hanley-Maxwell, Pogoloff, & Whitney-Thomas, 1998; Wehman, 1996). Partnering with families was a key requirement for every transition systems change grant funded by The U.S. Office of Special Education Programs during the past decade. Yet little evidence exists that true collaborative partnerships systemically emerged. Effective secondary transition planning, which seeks to form a collaborative partnership between service providers and families, must shift the emphasis back to the family, which will remain a constant in the lives of young adults with disabilities after they have left school.

Seven skill areas offer keys to the success of these partnerships. These are (a) gaining cultural competence, (b) exhibiting caring qualities, (c) communicating effectively, (d) offering helpful connections, (e) acting collaboratively, (f) using creative problem-solving, and (g) celebrating accomplishments.

(We need) regular communication, and relationships based on trust and appreciation for the strengths we come to the table with. (We need) less discussion of "shoulds" and "oughts" and more emphasis on what we can do. (Patrice Sell, Teacher/Coordinator) [AZ]

Gaining Cultural Competence

The 2000 U. S. Census data confirms the shifting demographics of the country from that of primarily Anglo with an African-American minority to a country with increasing numbers of families of Hispanic origin from all over the world and increasing numbers of families from Asia with varied ethnic and cultural backgrounds. Immigration from Eastern Europe, South America, and Africa also continues to change the face of America. In the next two decades, many communities will experience a shift to a multi-ethnic and mixed-race population. In contrast, the cultural representation of most educators and service providers do not reflect these demographic shifts.

Differing values, attitudes, and priorities develop within these cultural contexts. For example, not all cultures share a future orientation; in fact, this is a minority view among the

world's six billion humans. The typical U.S. citizen presumes equality between individuals and expects eye contact and self-assurance; this violates many cultural traditions. The American work ethic puts a high premium on doing things at the expense of being and becoming (Hodginkinson, 2000). The interpretation of disability and its relationship to strengths and needs may vary based on culture. The very conversation that transition service providers seek to have about future planning, self-determination, strengths and needs, and productive adult lives may contradict the expectations, experiences and values of families with whom they wish to partner. In addition to country of origin, every family and service provider exists within their own ecological context, differing in economic means, family systems, heritage, and education. All of these factors create occasions for cultural collisions.

When families and education or community service providers interact, which occurs during the transition process, each brings a level of awareness, competence, and confidence in what is about to transpire. The professional comes to this relationship with an awareness of the family's culture and competency. Families with a low cultural awareness have little tolerance for the cultural differences that inevitably exist. At the same time, the family enters the relationship with an understanding of the special education or adult service agency system that also may range from high to low. A family, with a high understanding of the system comes to the relationship with a different power position than one with a low understanding. High cultural competence by professionals and high system awareness by families is on optimal partnership. Low cultural awareness and low system awareness give educators or agency service providers the "power of position", which will not lead to partnerships with families. Power sharing is an essential component in collaborative partnerships; between families and service providers.

In reality, each of us is ethnocentric; that is, families and service providers see and interpret interactions and take action based on their own cultural contexts. Strength exists within diversity of

Indicators of Success
What would cultural competence look like to families in the transition process?

1. Service providers ask families about their language of preference and their cultural traditions with the goal of learning each family's unique traditions as they relate to providing transition services to youth with disabilities.
2. Service providers arrange meetings that include family decision makers and occur at times and places that respect family cultural traditions and ecological contexts.
3. Service providers recognize that each family's culture is unique, regardless of racial or ethnic heritage.
4. Families share ways in which they are assisting their children to develop independence within their family and community.
5. Practitioners are aware of their own ethnocentricity and attitudes toward other cultural, racial, ethnic, and socioeconomic groups and develop skills of suspending those attitudes that would deny the family contribution to the partnership.

thought and opinions, but so does the potential for conflict and misunderstanding-as most people have limited direct experiences with people from different culture and family contexts. Developing cultural competence requires practitioners to examine their values, beliefs, and attitudes and develop the skills of suspending judgment and of respecting the diversity of the families with whom they work. This must occur to begin to establish a level of trust in the partnership.

Exhibiting Caring Qualities

Inherent in special education and many adult services is jargon and bureaucracy, with a focus on forms, procedures, and documents. The meeting process that accompanies transition planning often promotes passive involvement by family members where families are talked to, rather than listened to. This approach sets up an unequal power distribution, which contradicts the notion of equal participation in the process and violates the principles of a partnership described earlier. In addition, educators and adult service providers often receive training that warns against the over-personalization of their interactions with family members as a way to maintain objectivity. Thus, meeting planning originates from the service provider needs rather than the family context.

Service providers do operate within a service delivery framework with standards and eligibility that often focus on deficits, and budgets that must be considered as part of the transition services negotiations. Service-provision jargon exists as a means of communication between and among service providers. Practitioners offer services tailored specifically to address student or client deficits. Service providers have rules, regulations, and guidelines to document family histories. The system is often slow to respond to parents while systemic policies and procedures are followed. These system attributes often create both an atmosphere of formality and a perception that the system concerns override the individual outcomes and family context. These characteristics may communicate that the system alone can solve the problem. Service providers may operate with the belief that families cannot understand the complexities of the system.

A family of transition-aged youth may have a long history of seeking services for the child with a disability. This history may include confrontations through formal complaints and due process, or this history may include the family's withdrawal from participation after years of passivity. These histories serve to distance the family and the service providers and challenge the demonstration of empathetic listening and reaching agreement on the joint interest of the group (Hanley-Maxwell et al., 1998).

Families often perceive interactions with school or community service providers as unsympathetic or uncaring (deFur et al 2001). From a partnership perspective, families want to see that education and community service providers share a joint interest in achieving successful transition outcomes and a willingness to actively work to achieve these outcomes; that is,

service providers share a personal investment with the families about the successful transition of the youth with a disability. Caring qualities such as listening and supporting, teaching and guiding, and celebrating success demonstrate to families that this joint interest is possible.

Indicators of Success
What would a caring partnership look like to families in the transition process?

1. Service providers listen to family stories and cooperatively identify supports that are needed for the family.
2. Service providers offer to hold transition meetings at times and places that support the family context as needed (e.g. in the home; with childcare provided; at the local library or faith community, etc).
3. Families report that service providers demonstrate belief that the young adult with a disability can achieve their transition goals.
4. Service providers suspend their judgment of family status or past actions; they do not blame the family for failures.
5. Family members understand the intentions of service policy and procedures as protecting the joint interest of the transition partnership and as means to supporting the transition effort.
6. The service provider system uses family feedback to improve policies and procedures to be more in concert with family needs.

The most important consideration is that there has to be an evident and established purpose for the partnership. Secondly, the plan needs to include a concrete communication strategy where there is continuous exchange of information. Lastly, the plan will require unconditional support from the school officials and community agencies
(Sergio Fernandez, Vocational Rehabilitation District Program Representative) [AZ]

Communicating Effectively

Parents value transition service providers who provide concrete and accessible information about transition services within the school and community setting. They appreciate not having to ask for information, particularly during this transition period when they are not sure what to ask for. They rely on service providers to teach them about the transition process and the transition service system, and see the family's role as teaching the service provider about the youth or young adult with a disability (deFur et al., 2001; Hanley-Maxwell et al., 1998; Wehmeyer, Morningstar, & Husted, 1999).

Communication is reciprocal. Parents must communicate their needs, fears, hopes, and frustrations. Service providers must communicate their constraints and needs as well. Families and service providers want honest, direct, and open communication.

Communication involves giving information and receiving feedback about the communication; it isn't finished when the information is given. Transition service providers report that they communicate frequently with families; that is, they call, they send letters, or they send messages via other means. They inform families that adult services exist and that transition planning will occur. Commonly, these are one-way once-a-year notifications that may not result in true understanding. To create and maintain a parent-service provider partnership, multiple communications that occur in multiple settings over an extended period of time will be necessary. Two-way communication enables families and service providers to set clear goals and to identify roles and responsibilities. Effective communication includes asking families for feedback to assess the clarity of the communication. Failure to communicate effectively (including using understandable language or means of communication) accounts for many conflicts in parent and school or community partnerships.

Indicators of Success
What would effective communications look like to families in the transition process?

1. Service providers ask family members for feedback about information that has been communicated.
2. Families openly give their impressions and information needs.
3. Families are able to describe the transition service system and the transition services and supports available.
4. Transition goals for the youth are clear, and families and service providers are able to describe how they will work together to achieve these goals.
5. Oral and written communications are understood by all.
6. Information provided by the family appears in transition plans as appropriate.
7. Information about transition services is provided in multiple ways such as brochures, videos, parent-student meetings, parent coffees, web sites, listservs, transition fairs, transition workshops.

Offering Helpful Connections

Partners share responsibilities; they engage in activities toward a common goal. They reinforce one another and support one another. They are equal. Family members demonstrate these mutual support characteristics in the transition partnership when they have been provided with the needed connections.

Connecting is about helping families network with others in the community who can enhance the family's knowledge and contributions to the transition partnership. Family members who want information on how to provide ongoing supports for an adult child with a disability want to meet with adult service providers. They also want a social network support system within their community that offers a backdrop for comparison to their own experiences-other families and other youths who have experienced post-school transitions. They may want information about resources at the local, state, or national levels. They may choose to participate in community organizations or agency structures that promote improved transition services.

Indicators of Success **What would effective connections look like to families in the transition process?**
1. School based service providers introduce families to adult service providers specific to their children's potential support needs. 2. Practitioners identify social support networks within the immediate community – for example, local advocacy groups, support groups, and other parents who have had similar transition experiences. 3. Practitioners offer structured opportunities (transition fairs, transition workshops, etc.) for families to learn about community transition resources and receive written materials describing community transition options and supports. 4. Youths with disabilities serve as coaches or mentors to other youths and young adults with disabilities. 5. Families offer to serve as coaches or mentors to other families in the transition process. 6. Family members serve on interagency boards and transition-planning groups.

Acting Collaboratively

Most existing professional special education literature of the past decade, including transition topics, makes reference to collaboration or teaming as an essential component of effective practice. Yet few exemplary systemic practices are documented.

Collaborative practices seek input from families, students, and service providers. True collaboration leads families and service providers to a merging of ideas, talents, and solutions. Collaborative solutions are those that would not have occurred without the mutual input of all team members. Collaborative partnerships recognize that opinions may differ and develop acceptable means for resolving conflicts. Yet collaboration cannot be forced; it is evolutionary. It takes time to build relationships.

The challenge for transition service providers seeking to create collaborative partnerships with families rests with taking the steps and time that fully include families and youths in the process. Collaboration assumes parity by all participants, shared decision-making, shared

expertise, and shared responsibility and accountability. As long as service providers believe they have all the solutions, and family members are perceived as lacking valuable expertise (or as expecting unrealistic services), family and agency collaboration will be blocked. As long as all transition services remain school- and agency-based and service providers assume all responsibility, then families or youths may not recognize their own capacity, nor feel ownership or commitment to the partnership. Service providers can help families identify their strengths and family resources that, in turn, will contribute to family empowerment in the transition process.

Collaborative parent and school-community service provider partnerships presumes active participation by all team members, with the role of parents or youths as team leaders developing as the transition process evolves.

Indicators of Success
What would effective transition collaboration teams look like to families in the transition process?

1. Parents and youth with disabilities are asked to share their transition vision.
2. Families (including the youth) are recognized for their expertise regarding the transition needs, interests, and preferences for the youth or young adult with a disability.
3. Transition partnerships use parent information in decision-making and problem-solving processes for transition services and programs.
4. Meetings are conducted in ways that encourage dialogue and listening.
5. Families feel safe in sharing information openly and honestly with service providers.
6. Families and service providers learn from one another.
7. Families and service providers share responsibility for implementing and evaluating transition plans.
8. Parents or youth with disabilities share leadership roles in the transition process with service providers.
9. Families and service providers identify community needs, evaluate transition services, and make recommendations for improvement.
10. Parents and youth with disabilities assume a leadership role in team activities (e.g., leading the meetings, bringing new resource ideas, evaluating the process).

Using Creative Problem-Solving

Individuals and agencies must establish new patterns of behaviors in order to embrace a collaborative-partnership approach for transition planning and services. Sometimes, the process or the problem seems too big and the solutions too abstract. Actually, it is possible to spend too much time analyzing and assessing the problem, and no time acting. It is better to take

a step at a time, where experience and reflection foster solutions, than to engage in all talk and no action. Families want to see transition plans being implemented, not just talked about. Where one begins, or how one begins, is probably not as important as that one begins.

Individuals must be risk-takers and action-takers to creatively plan and deliver transition services to youths with disabilities. In his book *The 7 Habits of Highly Effective People*, Covey (1989) outlines the difference between being reactive and proactive. Consider a transition team's attempts to develop transition services with few apparent resources available. A reactive response would be, "There's nothing I can do"; a proactive response would be, "Let's look at the alternatives." When agency policies and procedures seem to be a barrier, some people tend to use a reactive response, "They won't let me do that." The proactive alternative is, "I will persuade them to try a different approach." In dreaming of service alternatives, people reactively might say, "If only..."; a proactive response would be "I will..." Covey suggests that individuals take a day to evaluate the language around them for reactivity and pro-activity. Listen for reactive phrases such as "I can't," "They make me so mad," or "Yes, but" or for proactive language such as "I choose," "I will," or "I can." The challenges of working collaboratively requires team members to maintain proactive roles where creative action is the norm.

When all works well, each of us takes a piece of the process to assist the student in making a successful transition. (Name withheld, Youth Transition Program Teacher) [AZ]

Indicators of Success **What would creative, proactive parent-service provider partnerships look like in the transition process?**
1. Service providers and families brainstorm and evaluate options that differ from the traditional services usually offered in the transition process. 2. Transition services reflect interdisciplinary services and resource sharing. 3. Service providers take risks and try new ideas. 4. Families take risks and try new ideas. 5. Youths with disabilities take risks and try new ideas. 6. Service providers and families use "proactive" language and focus on solutions. 7. Actions that do not produce the desired results are learning opportunities, not failures.

Celebrating Accomplishments

Effective transition planning requires that families and service providers adopt a strengths-based or growth paradigm rather than the traditional deficit paradigm of disability and special education. The stigma of special education and focus on weaknesses does little to promote positive outcomes for youth. Strengths represent the avenues through which we learn and grow; abilities and skills shape our careers, our recreation, and our relationships. Promoting the abilities of youth with disabilities as they transition from school to post-school life supports this growth paradigm.

Collaborative partnerships take the time to celebrate transition accomplishments, both small and large. Education and community service providers spend a great deal of energy on process and procedure, often to the exclusion of congratulating themselves, families, or youths. Success builds both competence and confidence, which are essential skills for ongoing post-transition work. Celebrating the work of the group and of the individuals involved provides ongoing encouragement and time for reflection.

Indicators of Success
What would meaningful celebrations look like to families in the transition process?

1. Service providers focus on the abilities of youth and young adults with disabilities.
2. Families receive regular communication from service providers acknowledging small as well as large accomplishments toward transition goals.
3. Transition partnerships publicly recognize the successes and accomplishments of youth with disabilities in the transition process.
4. Service providers and families credit the partnership for transition successes.

Moving Forward

The essence of collaborative partnerships is the existence of mutual trust and respect between families and transition service providers. Trust emerges when patterns of positive behavior—cultural competence, caring, communicating, connecting, collaborating, creating, and celebrating—are predictable and when confidence exists that these behaviors can be depended on. Trust is not likely to exist after a first meeting as there is no history on which to build the trust, and individuals know little about interpreting the interactions that occur. For families in transition, their history with service providers will be the lens through which families view the first attempts at creating a partnership. In the same way, a practitioner's history with prior students, clients and their families will influence present interactions. This history and the openness with which people share their experiences and expectations may determine how long it will take to create an environment that allows trust and respect to develop. Sharing

reveals the transition stage of each individual. Collaborative partnerships will not result from a single planning meeting or a single event; they will require cumulative efforts and actions over time where service providers and family members consistently demonstrate collaborative transition partnership behaviors. Service providers who adopt a partnership philosophy, acting consistently in accordance with partnership principles, set the stage for families to willingly join the collaborative transition partnership.

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4

Parents as Evaluators and Decision-makers

Kris Schoeller and Ellie Emanuel

Parents have been IEP team members since the beginning of mandated special education services. They have participated to varying degrees in their child's assessment and planning process. During IEP reviews and evaluations, parents share their knowledge of how the year has gone and what progress they see on a daily basis at home and in the community. The 1997 amendments to IDEA promote parents' active participation in evaluation activities. Parents' assessment of the impact of school practices, programs, and curriculum have provided a valuable resource and support for those interagency teams.

What does it mean for a parent to be an evaluator and decision maker? How does a parent evaluate a school program? What are the core criteria that parents use when they make decisions and evaluate effectiveness for their own child's transition program and the system? How do schools determine the outcomes of their transition services? What knowledge and skills do parents need to be effective evaluators? These are the challenges this chapter will address.

We distribute parent and student surveys at the end of each semester and we have very low incidence of those surveys being returned. A greater amount of feedback from the parents and students would benefit us by allowing us to modify and adjust the program as necessary to meet individual and group needs more effectively. (Kim Glenn, Teacher Coordinator for Transition Services) [AZ]

Federal Requirement for Expanding the Role of Parents in Program Evaluation

Since IDEA (1997), parents have been formally included in the monitoring and evaluation process. The Office of Special Education Programs (OSEP) developed a multifaceted process for accountability that expands the role of parents in evaluation. As listed in the 2000-2001 Monitoring Manual (Office of Special Education Programs, 2000) each state will participate in an ongoing monitoring process with these phases:

1. Self-Assessment. The state will appoint and work with a steering committee composed of key stakeholders including parents, advocates, and persons with disabilities (this may be the existing State Special Education Advisory Committee or the State Interagency Coordinating Council) to develop and implement a self-assessment plan that analyzes the state success in achieving compliance and improving results for children, youth, and families.

2. Validation Planning. The steering committee works with OSEP to develop a plan to gather data. This data will include statistics from state and local districts as well as three to nine public meetings, held over a three-day period. These public meetings will include parents, advocates, school personnel, and representatives of other agencies that serve families. OSEP wants to assure a diverse representation and encourages states to reach out to minority populations, underrepresented populations, and people who live in remote areas in an effort to validate the self-assessment results. These public meetings will be held in a focus-group format.

3. Validation Data Collection. OSEP will then collect all the data and work with the steering committee to plan the reporting process. Data will be collected from visits to the state and local education agencies and from local programs and providers. The data will also include a review of documents with parents, students, administrators, teachers, and other providers. OSEP will hold a structured meeting with the state leaders.

4. Reporting to the Public. OSEP's report, which will be available to the public, will address strengths, areas that need improvement, and any areas of noncompliance. The areas that will be addressed include: general supervision, comprehensive public awareness, the child find system, family-centered services, early intervention services in the natural environment, early childhood transition, parent involvement, free appropriate public education in the least restrictive environment, and secondary transition.

5. Improvement Plan. The steering committee will develop an improvement plan that addresses both compliance and improvement of results for children and youth with disabilities.

6. Implementation of Improvement Plan. The state will implement the plan and evaluate its effectiveness.

7. Verification and Consequences. Based upon documentation, OSEP will verify the effectiveness of the actions taken and present rewards or issue sanctions for continued noncompliance.

Parents will be included as members of the steering committee to consider state and district policies and practices for all children and youth in special education. They will participate in focus groups to provide input on local school curriculum and programs, and be included in interviews and surveys about their own child. Federal, state, and local plans for identifying needs and strengths will include parent input and recommendations. Federal requirements have been clearly established by OSEP. Procedures at state and local levels are being developed, providing a prime opportunity for parent input.

Parents as Evaluators and Decision Makers at Multiple Program Levels

What roles can parents play as evaluators within the secondary transition process, and what do parents need to be effective evaluators and decision makers at multiple levels? Professionals can create an environment that makes parents feel welcome and effective. The benefits, challenges, and strategies for developing a formal process to include parent and youth input on the quality and effectiveness of transition services is outlined below (Beswick, 1990; Epstein, 1994).

Parent Role as Evaluator in Their Youth's Program

The majority of parents first become involved in evaluation through participation at the IEP meeting for their child. As they become knowledgeable about the disability, learn the language of physicians, psychologists, educators, therapists, and form trusting relationships with the professionals who support their family, they may become involved at the district, state, or federal level. Parents can become members of an advisory committee or advocates for policy and legislative actions. Involvement at this level expands their knowledge of laws, policies, practices, and impact of services for teens. Ongoing experience gives parents the expertise for evaluation at this level. However, parents will always refer to what did and didn't work for their own child. That is the primary expertise they bring as evaluators.

I try to steer my daughter's worksite placements toward her personal interests rather than what is most convenient. They have tried to be flexible in this regard. (Carol Sime, Parent) [MN]

With the new process for monitoring, it is critical that parent assessment of transition programs and services be valued. Parents who provide personal stories through advisory committees, surveys, and interviews can provide information about family needs, educational supports that work, and gaps in services. Parents bring a lifetime of experience and preferences to the transition team. They also bring intuition and family values as part of the evaluation process. They provide information to individual service providers that contributes to a whole picture of their child. Since the current system of transition planning does not designate a service coordinator or case manager of all interagency, health, and benefit programs for youth, it is often the parent who must take the responsibility to coordinate services. Parents may, in fact, be the only transition team members knowledgeable about the interaction and interface between systems. Certainly they are the only ones who truly know how these programs, services, and supports affect the family and youth with a disability. For example, a parent may discuss speech and language therapy's impact on a son's increased self-esteem and self-confidence during interaction with others at home.

It is also critical to understand that parents do not evaluate services and supports during transition as isolated interventions. Because special education was structured after the medical model, parents receive information from physicians, teachers, therapists, and others in a categorical structure. Parents have expressed their difficulty with this process. Much of the information provided during an IEP meeting focuses on what is "wrong" with their child. The goals and objectives that follow are generally written to "fix" or remediate the disability. Parents may understand that the disability has life-long implications. They are looking for the teacher who sees strengths, for the physician who understands the fears and pain and offers options for independence, and the school and community service provider who creates nurturing and caring environments. Parents want their children accepted exactly as they are (Bronfenbrenner, 1979; Schwab, 1988; Turnbull, 1999).

Parents use all the information from IEP meetings, advisory groups, and others to evaluate effectiveness of interventions based on the whole child. They are constantly asking questions such as, Is my child happy? Is he learning new skills? Does she have friends who really like her? What will he be when he grows up and who will be there support to him? Will she be ready for the challenges of adulthood?

Table I: Family infusion and assimilation of information

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Parental evaluation is a nonlinear process influenced by culture, religious affiliation, parenting styles, core values, and more. Life events and major changes in socio-economic and education levels influence decisions. However, for most parents of all races and cultures, economic and educational status, outcomes are measured based on quality of life, unconditional love and attachment, protection from harm, basic needs, and support for development. These decisions are also influenced by the interaction between family/child and extended family, community, available resources and policy. Few, if any, decisions are evaluated based on only one criteria. The past and current interaction between child and teacher, child and school, family and physician, family and societal attitudes all enter into the evaluation of any given program or service (Ballen & Moles 1994; Jeppson, 1995).

Table 1 depicts the immense ability parents have to take in new information about their child, meld it with their family structure, values, and priorities, and emerge with the ability not only to contribute to the long-term planning process for that child, but also to evaluate its effectiveness.

Parent Role as Evaluator and Decision Maker in Programs and Systems

The education and adult agencies will benefit from including parents as decision-makers and evaluators. Because parents are the constant and daily connection for their youth, they provide a richness of information and a cohesive, ongoing, long-term support for persons with disabilities. Most professionals who enter the fields of special education, rehabilitation, therapy, and social services do so because they care about people with disabilities. Professionals who translate that caring into collaborating with families build relationships that can lead to strong advocacy for changing policies and acquiring resources (Shields, 1994).

When parents evaluate the system, they provide a whole-child perspective and can clearly state what is and is not working within the categorical system. They have gathered information from multiple sources and put all the pieces together. As the catalysts that put the pieces together, parents can make the program more effective. For example, Susie works with her special education teacher on academic skills, a social worker on anger management, and a physical therapist on gross-motor skills. At the same time, the child is turning 14 and is beginning to question how she fits in with peers at school. The school staff may not be aware of the personal influences in Susie's life that may affect her performance. Susie's parents know all the pieces and can communicate what is occurring and what needs to be addressed. In this situation, Susie's need to focus on self-concept and peer relationships may be more important than gross motor skills or reading. Parents can support the professionals in looking beyond the immediate need or the current goals and objectives on the IEP to evaluate the whole child.

Prerequisite Environment, Knowledge, and Skills

OSEP's involvement of parents in evaluation offers a new approach that will increase information to federal, state and local program and policy administrators. This information will expand evaluations of special education programs and services beyond legal requirements to include quality, satisfaction, and outcomes. In order for parents to become involved in this process, they will need a welcoming environment as well as prerequisite knowledge and skills, which will vary based on the parents' level of involvement. For example, parents who participate in a state steering or advisory committee will need more knowledge and skills than parents who participate in a single interview about their own child's program.

Welcoming Environment

Regardless of the parents' level of involvement, practitioners must create a welcoming environment for parents. Parents must believe that the information they share will be valued and incorporated into any improvements or needs within their school or system. They must believe that people truly care about them and their child. Creating this environment has been a challenge for systems and organizations, which continue to struggle to increase parent involvement at all levels. Progress begins with the belief that parents do have valuable information and skills and are the experts on the whole child within a family system (Adams et.al., 1997; Swick, 1991).

The welcoming environment includes being comfortable with expressed emotion. Having a child with a disability brings a lot of emotion with it. The emotional cycle does not end with time, as often occurs with a single tragedy. Each unmet milestone renews the fear of the unknown for parents. An environment that empowers parents as evaluators allows emotion to surface and be part of the interview, survey, or advisory group.

Parents come to the table with a strong love and emotional connection to their child. They seek a partner in the teacher, a support in the social worker, and compassion and understanding listeners in all members of the planning team. Initially, parents will evaluate the effectiveness of a program based on their own experiences of its impact on their youth. As they are welcomed to become more aware of programmatic implications on other youth and more comfortable in their evaluative role, they are able to critique the program in a larger context beyond individual experience.

As youth with disabilities move beyond the school years into adult environments, parents may experience a sense of isolation, lack of contribution, or loss of belonging to a familiar service setting. When this occurs, practitioners in the adult setting will need to support parent participation in the unfamiliar system, including service evaluation. Additionally, parents will struggle with evaluating transition services if their child is not experiencing success. Parents can

learn coping and resilience, partnering and collaboration, if the professionals who treat, serve, educate, and support them provide a caring environment (Salembier & Furney, 1997).

Knowledge

Parents also need clear, accurate, and honest information in several areas before they become evaluators:

1. They must understand the impact of their child's disability on academics, vocational skills, independent living skills, and interpersonal relationships. They need support in synthesizing information gathered from a variety of sources. Practitioners may struggle to provide information in a holistic manner partly because they see themselves as educational or disability experts in a given field. Practitioners who communicate information about the youth must allow time for discussion. This allows parents the opportunity to understand and assimilate the information in a productive way, which will influence their satisfaction with the program.
2. Parents need information regarding services and systems which serve youths with disabilities and how they operate. They need to know options and menus for treatment, programming, support services, therapies, and interventions of all kinds within school and adult settings. Along with a list of choices, the expected outcomes for those services and supports will assist families in decision making and evaluation.
3. Parents need to be fully informed about the transition planning and implementation process and the legal requirements of IDEA and supporting legislation. They also will need information about the current political agenda and the level of commitment or restrictions from administrators as it affects programming, funding, and policies. Educators, administrators, and adult service providers need access to this information, and need to be able to transmit it to parents in clear and usable formats.

Skills

Although knowledge is vital, parents will also need to develop good collaboration, mediation, and communication skills. Often these skills are learned through trial and error. Providing advocates and effective parents as role models will increase these skills. Learning the benefits of mediation and collaboration will increase parent communication and effectiveness. Workshops to develop communication, collaboration, and mediation skills can also increase parental effectiveness as evaluators.

Table 2 summarizes possible evaluative role levels and respective knowledge and skills sets needed to fulfill those roles.

Prerequisites for Parent as Evaluator

Level of Involvement	Role of Parent as Evaluator	Prerequisite Conditions
State: Steering committee/ advisory council	1. Expert on their own child 2. Good communicator 3. Team member 4. Skilled in transition and disability	• Welcoming environment • Trusting relationship • Knowledge of multiple disabilities • Knowledge of impact of disabilities • Knowledge of transition • Knowledge of IDEA and IEP requirements • Knowledge of current programs/options • Knowledge of current policies, practices, and procedures • Knowledge of political agenda and funding issues • Knowledge of adult agencies • Knowledge of accommodations, modifications, alternative assessment
State and Local: Focus group survey	1. Expert on their own child 2. Good communicator	• Welcoming environment • Trusting relationship • Knowledge of own child's disability • Knowledge of impact of child's disability on life events and goals • Knowledge of transition and IDEA • Knowledge of current programs • Knowledge of adult agencies • Knowledge of accommodations, modifications, alternative assessment
Local: Personal interview	1. Expert on their own child	• Welcoming environment • Trusting relationship with professionals • Knowledge of own child's disability • Knowledge of impact of child's disability on life events and goals • Knowledge of transition and IDEA • Knowledge of current programs

Table 2: Prerequisites for Parents as Evaluators

Challenges to Including Parents as Evaluators

Parents

Parents may experience the following challenges in becoming effective evaluators and decision makers:

1. They may lack trust in the educational and adult service systems, which may interfere

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with their willingness to communicate openly with practitioners in that setting. They may perceive that practitioners do not listen to their concerns and issues, or follow through with recommendations.

2. Lack of time and energy is a concern for parents who struggle to manage work and family responsibilities in addition to any expanded roles within the systems serving youth with disabilities.

3. There may be a real or perceived lack of consistent case management or single point of contact for families who need ongoing information and support to build skills as evaluators. Because there is no designated point of contact for information and coordination of transition services, parents often are frustrated, confused, and exhausted. Some parents are so overwhelmed with the daily needs of their child or children that they want others to take a leadership role. Some parents want to be the "case manager" or service coordinator so that they can learn to navigate the systems and make the ultimate decisions for their family. These roles may change from year to year as the family cycles through medical and educational events, and as they acquire more knowledge and build resilience.

4. Parents may lack knowledge about how disability programs and systems work, which would be essential in becoming an evaluator.

Professionals

Practitioners may experience the following challenges in collaborating with and supporting parents as effective evaluators and decision makers:

1. Professionals may lack knowledge regarding family dynamics. They may lack education and training regarding how to work with families. They may have insufficient preservice/in-service information, experiences, or administrative support to build these skills and make this a priority (Powell & Graham, 1996).

2. Some practitioners may have had prior negative experiences with families which can influence professional attitudes. They may believe parents (a) are unrealistic, (b) use their power and influence to force others to do what they want, (c) say one thing but do another, (d) sabotage programs, (e) demand too much, (f) are overly critical, (g) don't tell the whole truth, (h) devalue their opinions, (i) are in conflict themselves, and (j) question their advice (Seligman & Seligman, 1998).

3. Because parents may lack background knowledge of how disability programs and systems function, practitioners may consider it time prohibitive to support parents' assimilation into evaluative roles.

Strategies for Assimilating Parents into Evaluator and Decision-making Roles

Although there are many challenges to including parents as evaluators, there are also many strategies that help. Parents operate comfortably within the system at a variety of levels. This may be, at its least intrusive, active involvement on behalf of their own children, or, at most, as an integral partner in systemic evaluation and change. Whether parents are involved in the state steering committee or participating in an interview, they will need to be knowledgeable partners in the development of the IEP, including present levels of performance, goals and objectives, and the expected outcomes of the educational program and services. The strategies listed below will help parents, youth, and professionals work together as evaluators of transition programs.

Training, In-service, and Policy Changes for Professionals.

Education and agency leaders should ensure that practitioners have information and support on how to work with families. System policies should encourage parent participation in evaluation. Creating an environment for parents and youth to feel comfortable and committed to participation in the evaluation process will require changes in policy and practice. Professionals need additional information and support in working with families and using a family-centered approach to communication, assessment, and planning. Professional training in the area of disabilities is often based on a "helper/provider" model. Educational, medical, rehabilitation, human services, and therapy models assess need and intervention, and professionals develop a plan based on respective areas of expertise. This model has merit in identifying needs and meeting criteria for services, but families and youth especially often want to be more than the recipients of services. There is a strong need to move from the helper/provider to family-support model, which will enable parents to see themselves as team members and become confident of their knowledge and contributions.

To begin the process of change to a family-support model that creates a welcoming environment, some key factors need to be in place:

1. Develop policies that define parent involvement and include parents in evaluation within each school, supported by the administration.
2. Invite a parent to speak as part of an in-service training, on the topic of "Having a child with a disability: what supports make it work?"
3. Contact the local parent training and information center and request information and materials written by parents about having a child with a disability. Use them as informational materials for professional development.

4. Request any community-based family service agencies (some are culturally specific) to provide a presentation on "working with diverse cultures."
5. Provide in-service and on-going support for teachers to learn how to create a trusting and welcoming environment.
6. Develop policies and practices that allow teachers, social workers, and others time within each week devoted to communication with families (phone, in-writing, or in person).
7. Develop evaluation interviews, surveys, and focus group questions that include gathering information about what parents and youth value, need, and see as helpful.

Transition Assessment Tools and Processes That Empower Families

As discussed earlier, parents, professionals, and youth need information about the disability that goes beyond diagnosis to understand how the disability will impact real life. When meeting with psychologists, physicians, therapists, and others, parents need to ask the questions, "How will this impact going to college? What supports will be needed to obtain and maintain a job? How will this affect developing relationships and socializing in the community?" Transition assessment is one way to gather and share important information. A good transition assessment will clearly show the interaction between disability and life goals. It will gather and provide information beyond diagnosis.

It is no longer helpful to focus on academic skills without also considering how they will affect employment, independent living, or post-secondary education and training. For a teen with a chronic illness, such as a seizure disorder, it is no longer sufficient to list the condition in present level of performance, along with medication for treatment. It is beneficial to note how the seizures will impact the job or living independently. Attention Deficit Disorder/ Attention Deficit Hyperactivity Disorder (ADD/ADHD) has been considered an emotional/behavioral disorder that impacts organization, ability to focus and attend, and complete assignments. In discussion during transition, it would be helpful to assess how the disorder will impact employment, developing relationships, or participating in a recreational activity.

There are many excellent transition assessment tools. If parents are to be evaluators and decision makers for their children, they must have accurate information and a systematic process that gathers and organizes information from and for them. Conduct a parent interview, survey, or talk to parents informally to increase their ability to plan for the future. A very simple assessment may be most beneficial. Consider the questions listed below as part of the transition assessment for students and parents. Table 3 represents a set of questions for each of the transition areas.

Individual Transition Assessment Questions:	IEP Areas to Address:
• What is the current situation? ▶	Present level of performance
• What is the desired future situation? ▶	Future adult outcomes
• What are barriers to the goal? ▶	Needs
• What assistance is needed? ▶	Accommodations/modifications/activities
• What are specific strategies to address the needs and goals? ▶	Goals and Objectives

Table 3: Transition planning questions pertinent to IEP development

Teacher and IEP managers like this tool because each of the questions and answers easily transfers to the IEP. The "current situation" becomes the present level of performance. The "desired future situation" becomes the future adult outcomes. "Barriers" can be included in the needs section. "Assistance needed" and "strategies" move into the accommodations and goals/objective section of the IEP.

Including Parents in Advisory Groups and Interagency Committees

Parents can play a critical role in program or policy development and evaluation. For them to become effective evaluators of school programs and local, state, and national policies, there must be a shared identified plan of evaluation. As they work to bring the language of IDEA of 1997 into practice, school districts, as well as state education, rehabilitation, health and human service departments can include parents in developing strategic evaluation plans. When parents and youth are included, they develop ownership and investment in the success of programs and practices. Evaluation is not an end result, but an ongoing consideration for outcomes for all partners. When all members develop a purpose for evaluation, and collectively design measures and methods to gather information from key stakeholders, the evaluation process joins all stakeholders together to identify what works, what doesn't work, and how to improve services. Youth and parents often bring extremely creative solutions to budget and resource problems (Davies, 1997; NCREL, 2001).

To address some of these issues, parents, youth, and professionals can partner with others in creating ongoing community transition interagency committees and special education advisory councils. They can meet regularly to:

1. Receive information about transition, local programs, youth leadership, adult services, post-secondary education, and additional areas of interest and need.
2. Identify gaps in services.
3. Brainstorm solutions that affect entire school districts and community service systems.

4. Build leadership and collaboration skills between families, schools, and community agencies.

5. Build a process that incorporates stakeholder perspectives into evaluation activities.

Feedback from these interagency teams to the monitoring process will allow improvement in the transition programming process.

One of the tasks for these committees and advisory groups should include developing the questions to be used in focus groups and surveys. Parents can be involved in the construction of the surveys, focus group questions, or interviews. Questions asked in a survey, focus group, or interview may include open-ended questions and a place for comments to allow parents the opportunity to respond from their perspective and current level of understanding.

If surveys and interviews will be conducted in person, it will be helpful if the surveyor is another parent or professional who has been trained in working with families. If the surveys and interviews will be conducted through the mail, a cover letter that explains the rationale and use of the survey will increase parent response.

There are some essential requirements when using these tools:

1. Assure confidentiality.

2. Provide a time and place convenient for parents.

3. Provide clear and sensitive training for the interviewers, making sure the instruments are culturally sensitive (including translating into native languages) while ensuring that consistent interview practices will result in valid data collection.

4. Ensure that accommodations are made for parents with disabilities (i.e., reading level, Braille).

5. Use focus groups whenever possible, since the group dynamics support parent-to-parent interaction.

6. Include questions that will solicit parent and youth perspectives from a broad holistic life picture, including some that include relationships, socialization, recreation, and life satisfaction.

In order for parents to be effective evaluators, there must be an ongoing process in place, such as surveys, interviews, focus groups, or testimonies. Efforts by professionals who request and value family input on programming, support services, and quality of interaction will strengthen the entire transition planning and implementation process.

Indicators of Success
What would effective evaluation and decision-making activities by parents look like during the transition process?

1. Professionals are receptive to parent feedback and have developed practices to actively solicit it.
2. Parents are knowledgeable about transition planning mandates and guidelines.
3. Parents have the necessary information regarding services and systems serving youth with disabilities and how they operate.
4. Parents would be able to function as experts on their child's disability and its effect on learning in multiple environments.
5. Parents have developed communication, collaboration, and mediation skills to express perceptions of program quality in ways that will be constructively heard.
6. Parents function as full team members in diagnostic processes, as well as evaluation of program effectiveness.
7. Parents feel comfortable moving beyond evaluation of their own children and are willing and able to be involved in systemic evaluation at broader levels.

Conclusion

The past system of monitoring and evaluation for individual IEPs, as well as local and state educational plans, focused primarily on paperwork compliance. Federal, state, and local monitors will now gather information from direct service providers, parents, and youth to evaluate results, satisfaction, and progress, and inform continuous improvement.

Using multiple processes, instruments, and methods to provide information and gather information will increase parent and youth participation as evaluators. Incorporating parent and youth perspective in professional development, team training, organizing community transition interagency committees, and community involvement are all strategies for evaluation that will enhance the quality of life for youth with disabilities and their families. Undertaking these strategies also will build the critical support professionals need in order to meet the needs of today's families and youth with disabilities in the transition process from school to adult life.

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5

Parents as Trainers, Role Models, and Mentors

Sharon M. Kolb

The purpose of the chapter is to explore the roles of parents supporting other parents in planning and implementing transition goals for their children. Not only can parents be an excellent source of information regarding their children, their children's disability type, and the family system within which they operate, they also are a valuable resource to other parents and professionals. A collaborative model can facilitate parent involvement as trainers, role models, and mentors in the transition process.

Evolving Practices

Policy changes in special education have enhanced the role parents play in the educational processes of their children with disabilities. Parents have moved beyond the traditional roles of information receivers into roles of case manager, advocate, mentor, trainer, and program evaluator (Santelli, Turnbull, Sergeant, Lerner, & Marquis, 1996). Consequently, parents have expanded their roles beyond the needs of their own children into new functions by assisting other parents to meet the demands of accessing transition services for their children.

Parents in these outreach roles are often involved in various parent groups at local, state, or national levels. Parent groups offer support and training to parents through mentoring. In parent-to-parent programs, mentoring involves linking a new parent with an experienced parent with similar qualities or issues (Santelli et al 1996). Parent mentors act as advisors, consultants, and role models. Ideally mentors have enthusiasm about the issues parents with disabilities encounter throughout the transition process, a desire to assist other parents in

developing their awareness issues and skills, a positive outlook towards the process, a willingness to learn, communication skills that facilitate interaction and collaboration, and patience.

At times, parents assume the roles of mentors, trainers, and role models without formal training. Parental personalities, knowledge levels, and experiences may naturally lead certain individuals into assuming these roles. However, even parents with these natural abilities could benefit from more formalized training.

We encourage and help parents to become mentors. By doing this, they can empower themselves to become role models. They can support other parents in doing the same, resulting in a network of professional role models and mentors. (William J. Schmidt, Director of Day Program Services) [AZ]

Parents can be role models to other parents, teachers, children, and professionals in their communities. When parents who support their own children with disabilities are involved in transition activities and interagency linkages, they start a series of ripple effects. They create opportunities to network with other parents and form relationships that enable other youth to navigate throughout the community. These families, then, become more connected with the appropriate programs and services. Other parents who are touched by their actions are inspired to become involved in their own ways. The ripples expand.

The Importance of Supporting Parents in Emergent Outreach Roles

It is critical that parents are supported in roles as trainers, role models, and mentors because of the positive benefits to all stakeholders involved in the transition process (Guy, Goldberg, McDonald, & Flom, 1997). The major stakeholders in the transition process are young adults, parents, and school and agency practitioners. Students benefit by the increased knowledge base and involvement of their parents in the transition process. Parents benefit by developing a support and training network of individuals with similar concerns related to transition issues. School and agency professionals benefit from the shared ownership and responsibility; they grow from their exposure to the knowledge, perspectives, and assistance from parents. All stakeholders benefit when parents are supported as mentors, trainers, and roles models for the following reasons: (a) linkages are developed, (b) parents provide excellent recommendations to other parents from both business and financial perspectives, and (c) par-

ents have specific knowledge of protocol, contact persons, and strategies to move through the system (Carter & Harvey, 1996; Matthews & Hudson, 2001).

Examples of this may be evident through the actions parents have taken in advocating for services and funding (i.e., insurance, SSI) for their children. Sharing these experiences can help other parents develop and implement the most appropriate transition plan for their young adults.

Prerequisite Knowledge and Skills for Trainer, Role Model, and Mentor Roles

To fulfill this role parents need to be aware of:

1. Information about their own child's disability and the impact on his or her functioning, curriculum, and outcomes, as well as other disabilities represented in families in their network.
2. Legislative mandates and procedures, especially related to transition.
3. Local program and community resources and services, including their availability, eligibility requirements, service options, application procedures, and policies.
4. Parental acceptance stages in adjusting to having a child with a disability.
5. Cultural diversity of the community and differences in values and communication styles.

Parents need the following skills to effectively serve in this role:

1. Communication and listening skills that will enable them to hear and understand the needs of other parents and identify underlying themes.
2. Identification of the parental stage of acceptance and the ability to respond appropriately.
3. Organizational skills to be able to locate appropriate agencies and individuals for referral purposes.
4. Creative problem solving, recognizing that each parent will present a different scenario.

Challenges in Preparing Parents for the Role of Trainer, Role Model, and Mentor

In order for parents to be prepared for this role, there are three challenges that must be addressed: (a) narrow view, (b) parent and professional perceptions, and (c) availability (Guy et al. 1997).

Narrow View

Parents tend to view disability and transition issues solely from the perspective of their child, thus limiting the value of the parent's contribution to the whole group (Guy et al. 1997). They may only have information about their own child's disability and the challenges they have faced. They need a broader base of information about the range of disabilities and transition planning procedures and outcomes before they will be able to support other parents.

Parent and Professional Perceptions

Practitioners need to examine their own perceptions about the value of parent contributions in this role. If they believe that parents' contributions are somehow of less value than their own expert contributions, they will have difficulty empowering parents to assume this role. Parents also may have perceptions that could interfere with their ability to function in this role. Friesen and Huff (1990) identified parental concerns of co-optation, that is, their concerns of being dominated as they were assimilated into the educational system. One example of co-optation is when a parent feels reluctant to express his or her feelings because it may be perceived as challenging the professional's expertise and potentially cause conflict in future professional interactions. An awareness of possible conflicts between parent and professional perceptions will lead to an open discussion of the issues and can make an important contribution to building partnerships between parents and practitioners.

Availability

There are availability concerns in working with parents to become trainers and mentors–both availability of parents and availability of support from professionals. Specifically, many parents are unable to fulfill the numerous demands of mentorship, such as time and financial constraints, and other commitments (Friesen & Huff, 1990). These concerns also include difficulties in contacting parents, scheduling conflicts, and parent withdrawal from involvement when they did not feel validated by school and agency practitioners (Guy et al. 1997). Friesen and Huff also commented on the high expectations that some profes-

sionals place on parents, such as presuming that parents can readjust their work and home schedules to attend meetings scheduled at convenient times for educators or finding child care in order to attend meetings. Time issues, for both parents and professionals, must be addressed. Finally, the availability of funding to support parent training is another significant barrier to assisting parents in their role as trainer, role model, and mentor.

Resolving these issues requires careful communication to identify the positions and perspectives of each individual. Parents need to understand the legal and systematic constraints that professionals must operate within to support their agencies. Professionals and parents need to discuss these constraints to maintain positive relations with all stakeholders. One aspect of these constraints is the challenge some professionals may encounter in the negative backlash that can occur from supporting and encouraging parents to be more assertive and advocate for their needs. A conflict of interest may arise that could jeopardize collaborative efforts. Parents' anger and frustration with the legal system or inadequate resources may be inappropriately directed at the same professional who provided mentoring and support (Friesen & Huff, 1990).

Strategies to Prepare Parents to Assume the Role of Trainer, Role Model, and Mentor

There are a number of strategies that have been developed to prepare parents for this role. Practitioners who identify parents as likely trainers, role models, and mentors may help them develop skills to assume these roles or may connect them with other resources that are available for this purpose.

Person-centered planning has been the most incredible tool I've ever used. It makes so much difference in a student's attitude. Some of the students that come into (my) class are surprised to hear they have a disability, much less understand what that disability is. Discussing it openly with them makes it less mysterious. They are also better informed and become self-advocates, not only at school but at home with parents. That self-advocacy and personal responsibility encourages parents to become better role models, trainers, and mentors. Both approach the future more as adults.
(Patrice Sell, Teacher/Coordinator) [AZ]

Parent-to-parent Models

Numerous agencies and program models have been established to provide support and training to parents of children with disabilities. Parents training parents models have been identified in the literature as proven models that can help parents collaborate with other parents and professionals to meet the transition needs of their children with disabilities (Friesen & Huff, 1990; Kroth & Otteni, 1983; Matthews & Hudson, 2001; Salembier & Furney, 1997; Santelli et al., 1996). Parent-to-parent programs are designed to provide information, emotional and social support, and advocacy training specific to individual family needs. New parents are matched one-on-one with experienced parents (Santelli et al. 1996). Creating an environment of membership and belonging is a major focus of parent-to-parent groups. These parent groups are designed to help parents overcome feelings of isolation, develop a support network of peers, and establish an environment that encourages a community of learners (Carter & Harvey, 1996).

Starting Parent-to-parent Models

When determining what information to share with parents and how to disseminate this information, it is critical for professionals to evaluate the specific parent audience and gather input from parents. The first step, therefore, would be to collect information regarding interest and support from the community. Strategies for gathering pertinent information can be accomplished by (a) connecting with a few established stakeholders (parents, administration, agency personnel, community members, teachers), (b) creating a parent survey ascertaining areas of interest, and expertise, (c) establishing if there is parental interest in meeting together, and (d) identifying parent backgrounds, skills, talents, and areas of needed support. After collecting this initial data, the group can convene and begin to brainstorm strategies that members are willing to support and implement. In this planning stage, the role of parents as trainers becomes a critical component in ensuring program success.

We had informal support groups—getting together around an issue and helping one another examine possibilities and share what programs work and those that do not (Diane H., Parent) [MN]

Providing Formalized Training

Accessing formalized training can expand the skills of parents who are currently training and mentoring other parents. Formalized training can provide a solid knowledge base for parents who want to serve in these roles but require specific information and training to develop new skills and enhance their current skills (Guy et al., 1997).

There are various training resources available for parents. Practitioners need to be aware of the resources at the community, state, and federal levels so that they can share information about availability and accessibility of training venues and resources. Each state has one or more federally funded parent training and information centers that are charged with assisting parents in understanding the special needs of their child, providing parents with information about child development, and helping parents to acquire the necessary skills that will allow them to support the implementation of their child's IEP or IFSP (IDEA 300.24.7). The PACER Center in Minnesota has a federal grant to provide coordination and technical assistance to all federally funded parent centers. More information about services and programs as well as a list of state centers can be found at www.pacer.org.

National parent information and training centers have developed collaborative training materials like the one published by the Parent Educational Advocacy Training Center (PEATC) in Virginia. PEATC offers a transition series for training parent and professional teams called NEXT STEPS. Workshops are presented by a trained team that consists of a parent, educator, adult service provider, and a student. The training materials include a trainer's guide with instructions for activities, flow charts, overhead materials, materials for participants, and a videotape entitled "Understanding Special Education" (PEATC, 2001). The NEXT STEPS training involves eight workshops (PEATC, 2001):

1. Transition: Making it in the Real World
2. Transition Plans: Roadmaps to the Future
3. Self-Advocacy and Supports: Keys to Independence
4. Moving On: Life in the Community
5. Getting Ready: Preparing for Work While in School
6. Planning Ahead: Future Finances and Support
7. Adult Life: Effective Partnerships
8. Adult Life: Accessing Services

The Appendix contains an annotated list of resources that would be a good starting point for practitioners and parents who want more information about education and training models.

Parent-driven Information Sharing

Because of the vast experience levels of parents, they bring a valuable perspective to other families of children with disabilities. Below are strategies implemented by parents working with other parents with practitioner support. Practitioners who are aware of the multiple benefits of parent-to-parent mentoring, training, and role modeling take the initiative to empower parents to this level of leadership.

Special education parent support groups. Parents and special education practitioners collaboratively lead monthly meetings, discuss relevant topics, and provide training in advocacy areas. These groups connect parents with educators and other parents to provide a general knowledge base of transition topics and other related services.

Transition seminars. Practitioners collaborate with parent trainers to provide support and training to other parents about transition-related topics. Topics can include community resources such as school-to-work programs, supported employment, work and life skills, job development, occupational matching, workplace supervision, functional assessment, and futures planning. Trainers should provide contacts, timelines, and information describing supportive agencies.

Parent match or parents paired with parents. Parents and educators organize parent mentor connections to match parents who are experienced in certain areas with parents who are about to go through a similar experience or who need support.

Parent-to-parent transition section in the school newsletter. Schools mail out a newsletter to all families in the community. A section of this newsletter, developed in collaboration with educators and parents, is devoted to addressing parents concerns related to areas of transition. Because of the community-wide distribution of the newsletter, numerous community members and agencies have access to the information.

Personal and professional contacts. Parents who have personal and professional access to experts in medical, health, financial, insurance, legal, and advocacy areas could facilitate opportunities for these individuals to share their expertise with other parents at transition seminars, PTA meetings, or parent-to-parent meetings.

Parent presentations to schools. Parents speak to classes, students, and teachers about their child's disability to provide information that will smooth the transition from one level to the next. Information is shared at different levels of transition, e.g., from early childhood services to elementary school, elementary school to middle school, middle school to high school, as well as high school to adult environments. Parents share strategies and accomodations that allowed their child to be successful in new school or community environments.

Parent presentations to organizations. Parents present information about their child's disabilities to parent and service organizations to help create a level of understanding about different disabilities. Community contacts are established and parents are linked to potential resources.

Parent social night. Parents can socialize and network with other parents in a more casual atmosphere. Parents can informally exchange ideas and strategies that have been effective for facilitating transition services for their children.

Reading club. Parents form reading groups exploring current literature in the field of special education and discuss transition relevant topics.

E-mail discussion groups, web sites, and E-newsletters. Parents develop a newsletter that can be submitted online to other parents. Parents generate and contribute topics and information listed in these Internet mentoring tools. Valuable topics include examples of clear IEP transition goals, announcements of beneficial training seminars, and strategies for increasing student and family involvement in futures planning.

Indicators of Success
What would effective parent trainer, role modeling, and mentoring practices during the transition process look like?

1. Practitioners have an increased awareness of the benefits and purpose of parents as trainers, role models, and mentors and frequently refer parents to other parents.
2. Parent mentors are identified as valid resources by other parents and practitioners.
3. Parents report the support and information they receive from other parents are valuable.
4. Parents who have been mentored are prepared to collaborate as partners with practitioners.
5. Parents are empowered to mentor other parents in the transition process.

Conclusion

Parents and professionals acknowledge the importance and value of parents networking with other parents. These networks can provide an avenue to share information, expertise, and resources that can benefit families striving to meet the transition outcomes for their children. This chapter was designed to provide strategies that can help in the facilitation of parents as trainers, mentors, and role models as a starting point to generate new strategies. The possibilities are limitless due to the varied contributions of parents, other family members, practitioners, and other stakeholders. The contributions of educators and agency professionals is critical to create an environment in which parents are enabled to fully contribute to all aspects of educational and transition planning and implementation for their children.

Appendix

Web Resources

- **ACT Inc.** - Information for Life's Transitions: www.act.org/ is an independent, nonprofit organization that provides educational and career services to students, parents, and professionals in schools, businesses, and government agencies.
- **Employment & Training Administration** http://wdr.doleta.gov/research/ The labor and training agencies of the U.S. government set up Training Technology Resource Centers (TTRC) to help create a system of employment and training services that address the topics of school-to-work, job training, corporate involvement, career resources, and skill standards.
- **Family & Advocates Partnership for Education (FAPE)** http://www.fape.org FAPE is a project that aims to inform and educate families and advocates about the Individuals with Disabilities Education Act of 1997.
- **Federal Resources for Educational Excellence (FREE)** http://www.ed.gov/free FREE provides numerous resources supported by agencies across the U.S. federal government. Vocational education is included in the resource list.
- **Fundsnet Online Services** http://www.fundsnetservices.com/ Fundsnet provides a wide variety of grants, scholarships, and financial aid resources.
- **National Center on Secondary Education and Transition** http://www.ncset.org NCSET provides assistance in secondary education and transition outcomes for families of youth with disabilities by coordinating efforts of national, state, and local agencies.
- **National Coalition for Parent Involvement in Education (NCPIE)** http://www.ncpie.org/ NCPIE is dedicated to establishing effective family, school, and community partnerships.
- **National Parent Information Network (NPIN)** http://npin.org. NPIN is a research-based network that provides information about the process of parenting and family involvement in education.
- **National Transition Alliance (NTA)** http://www.dssc.org/nta . NTA supports students with disabilities postschool success through national collaboration with universities, nonprofit services, business organizations, and national education associations.
- **Parent Advocacy Coalition for Educational Rights (PACER) Center** http://www.pacer.org PACER, based on a parents-helping-parents model, provides assistance to families and materials for parents and professionals across the nation.

- **Parent Educational Advocacy Training Center (PEATC)** http://www.peatc.org/ PEATC offers training opportunities for parents and professionals who are interested in developing courses for families. A training series called NEXT STEP focuses on skills and information needed to help students achieve transition goals.
- **Partnership for Family Involvement in Education** http://pfie.ed.gov/ PFIE was established by the U.S. Department of Education to offer resources, funding, and conferences relevant to supporting family involvement in education. The organization's role is to provide a network of support for businesses and organizations across the nation to promote educational effort within the community.
- **Secondary School Educators, Menu for Vocational Education** http://7-12educators.about.com/education/7 12educators/msubmenuvocation.htm Topics include connecting coursework to careers, lesson planning, and school to work: career and program resources.
- **Support and Training for Exceptional Parents (STEP)** http://www.tnstep.org STEP is a statewide family-to-family program in Tennessee, providing advocacy training, information, and support services to parents of children with disabilities.

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6

Parents as Instructors

David F. Bateman, Kim Bright, & Amy Boldin

The family is the single most powerful force in preparing adolescents with disabilities for adult life. Because parents are there across the youth's lifespan, they hold the unique position of life teacher. However, parents need support and information to effectively fulfill the role of instructional partners with practitioners. Thus, a strong partnership between parents and professionals who perform educational duties on a daily basis is an essential element in planning a successful transition to adult life (Berry & Hardman, 1998). As students with disabilities approach adolescence, the alliance between home and school becomes increasingly important. To meet the challenges of planning for an adult child with a disability, it is critical that special education professionals mentor and support parents through the process by valuing parental roles and providing parents with the tools they need to traverse the transition planning process (Schoeller, 1994) and play an active role in daily delivery of supportive instruction.

I would like to see parents be more interested and involved in planning for their child's future earlier than when they are a senior in high school. Students enjoy taking tours of colleges, community colleges, and technical schools, and if parents were more involved, this would give them more motivation and confidence. (Leslie Lassen-Mohn, Special Education Team Leader) [AZ]

Primary Domains of Parent Instruction

For youth to be successful in adult life roles and responsibilities, they depend on instruction and reinforcement from their teachers and parents. While educators initiate the instruction in basic skills for independent living, parents continue to instruct and supervise students' learning in home and community settings. This chapter focuses on two primary domains of instruction that especially benefit from instruction and practice across settings: self-determination and life skills application.

Self-determination Instruction

Supporting Parents as They Transfer Advocacy Responsibilities

Parents make decisions for their children throughout most of their childhood: Where to live, what's for dinner, where to attend school. For families with children who have disabilities, there are other early decisions such as what services their child will need and who will provide them. Parents also make decisions about whether services are appropriate and effective in view of their long-term goals for the child. It is widely recognized that parents are the best advocates for their children because they have lived through their medical histories and educational struggles. They know what strategies have worked and which ones were not productive.

When children reach adolescence, they begin to make some of their own decisions and, generally, parents encourage this process as an important step in gaining independence. For children with disabilities, other issues complicate the picture, and parents have mixed feelings about encouraging their child's independence. Yet, it is vital that they encourage this natural stage in the maturation process, starting the skill development early. Once the student has graduated and left the special education protections under IDEA 1997, the need for decision making and advocacy must transfer from parent to youth. Advocacy skills provide people with disabilities tools to assure that their rights are protected and all reasonable services are provided (Pleet & Grigal, 2000).

Some examples of advocacy opportunities include: (a) requesting needed accommodations from college instructors, (b) deciding whether, when, and how to disclose a disability when applying for a job, (c) filing a complaint under the Americans with Disabilities Act if a public restaurant is not wheelchair accessible, and (d) communicating desires and needs to a personal care attendant. While school and adult service providers work with adolescents to build their self-determination and advocacy skills, parents play a more important role in this process. They will need support and guidance from practitioners in passing the advocacy responsibilities on to their children.

Practitioners can support parents as they foster three key skills in their children: (a) practice making decisions, (b) understanding the disability, and (c) learning to advocate (Pleet & Grigal, 2000). Parents can and should begin this skill development at the earliest possible age.

1. Practice making decisions. Children can begin to make small decisions early, including what to wear and what to order at a restaurant. Their confidence will grow from these experiences as will their learning from making choices they regret later. How many adults have learned to listen to the weather after being caught in a sudden downpour without an umbrella? Yet, children with disabilities are often protected from making any wrong decisions. This makes them afraid to take risks. Parents need to be encouraged to set up decision-making opportunities while ensuring that the consequences are not devastating. In adolescence, students become ready to make more important decisions such as course selection and job choices. Parents can encourage their children to make decisions, both large and small, and then help them understand how those decisions affect their lives (Pleet & Grigal, 2000).

2. Understand the disability. Adolescents with disabilities need to understand what disability they have and how it affects their lives. More importantly, they need to know how to appropriately explain it to others. Practitioners should ensure that parents understand the results of diagnostic evaluations, the disability diagnosis, and the educational and transitional impact of that disability on the youth. When parents have all this information, they are more comfortable in supporting their youth and in ensuring that the adolescent understands the same information. School personnel (counselors, psychologists, and teachers) and adult service providers also can provide a valuable support in explaining this information using straight talk without jargon to both the youth and the family. By discussing the disability frankly, but positively, professionals move it from "embarrassing secret information" to a matter-of-fact personal descriptor such as eye and hair color. For example, "It's a fact that Sandy has an auditory perceptual learning disability that makes it difficult for her to learn from hearing. Yet, if she can read the material, she can learn just fine." It is important that practitioners and families work together to ensure that the youth will have the same positive messages about their disability in school and at home.

3. Learn to advocate. First, students must learn what accommodations, modifications, and supports work for them. Although these are terms students generally don't know, they can and should begin to use them. They need to know if they need extended time, graphic organizers, books on tape or disk, a notetaker, or modified assignments. Secondly, they need to know when to request these accommodations. On the project due date or after the test is too late. Usually, speaking to the instructor or employer privately ahead of time works well. Finally, students must learn how to ask. They will need to practice with their high school teachers to build confidence before asking college professors or employers for needed accommodations. Parents and educators can

also encourage students to practice advocacy at their IEP meetings, by speaking up to explain their future goals and summarizing their present levels of performance in the various domains. They will be expected to voice their goals with their rehabilitation counselor when developing the Individual Plan for Employment.

Pleet & Grigal (2000) summarize the importance of starting this skill development early:

> "Adult service providers and college support staff often lament that students do not know anything about their disability. It is as if no one has ever told them why they received special education services or how to deal with their disability. Students who have learned basic advocacy skills and have learned to take responsibility for their decisions and activities in their lives will be better able to cope with the challenges of the adult world. More immediately, students who know how they learn best and can ask for needed accommodations and modifications are more likely to be successful in school (p. 98)."

We would enjoy having parents participate as mentors to the students. This could take the form of parents being guest speakers, allowing students to job shadow or tour work facilities in which parents are employed. (Kim Glenn, Teacher Coordinator for Transition Services) [AZ]

Supporting Parents as They Prepare Students for Futures Planning

For parents to be integrally involved in assisting their teens to acquire necessary skills and make informed choices, parents need information throughout the journey. As the vision and goals of the student are shaped within the transition planning process, family perspectives should be considered to an equal degree as those of the professionals (Blalock & Patton, 1996). Schools must provide parents with information on training sessions on topics such as postsecondary education options, work-force issues, independent living, financial planning, and agency involvement. Embedded in these sessions should be the concept that once the student leaves public school, the service-delivery system changes dramatically. Young adults with disabilities and their families must move from a familiar system within the public schools into an unfamiliar and uncertain adult services system (Summers, 1986). Moreover, unlike the educational system, which entitles all children with educational handicaps to receive services, the adult service system requires eligibility (Moon, Inge, Wehman, Brooke, & Barcus, 1990). Parents need to prepare for this reality and the possible limitations of adult services. For parents, this means developing relationships with agencies that might provide services. It also means that parents of students with disabilities may have to continue their

focus on teaching skills longer than parents of children who are not disabled, due to varying degrees of readiness for independent living.

Although parent involvement in the IEP process is mandated under the provisions of IDEA, the variability and inconsistency of parent involvement is well documented (Harris & Associates, 1989). Given this variability, it becomes critical for schools to develop systematic strategies that promote and support active participation in the transition process. If practitioners assist parents in coming to terms with their youth's disability and its impact on adult life, parents will be better equipped to support the youth in developing self-knowledge.

Parents need to consider what the child's transition to adult life may involve while their child is still in elementary school. In addition, parents need to be encouraged to think about their teens' level of expected independence in work, education, finances, living arrangements, community access, and recreation. Keeping a long-range goal in mind will give parents a sense of control and order in the transition process. Special educational professionals can help parents start thinking about transition early by underscoring the importance of transition from the day students are identified and placed in special education. For example, if transition planning goals are part of every student's IEP from identification onward, transition will likely be considered in the future. Coupled with planned transition activities at every grade level, the transition planning component could be a powerful reminder to parents that the end goal of their child's special education is to prepare them to lead productive and independent lives to the greatest extent possible.

Parents can support their exceptional teens by openly discussing future goals and interests. In addition, parents can help their teens prepare for the transition planning meeting by supporting their goals and dreams for the future and helping them develop the skills necessary to be full participants in the transition planning process. Teachers can also promote student participation by supporting parents' involvement efforts. Parents and teachers can develop checklists of strengths, needs, and interests for the family to complete together before the meeting. Skills related to self-care, dressing, cooking, personal safety, travel, workplace skills, social interactions, leisure activities, higher education and training, and adult services should be included. Finally, parents need specific information about adult agencies and services. With familiarity of available resources, parents, youth, and practitioners can most effectively develop a focus and plan for the future.

We are always working on independent living skills, especially personal care, preparing food, and making purchases. When we see job applications displayed, we take them home for practice. (Carol Sime, Parent) [MN]

Supporting Parents as They Prepare Students to Participate in Their IEP Meetings

Strategies prior to the IEP meeting. Both parents and professionals can ensure successful student participation at transition planning meetings by following the guidelines for successful student participation, adapted from Berry and Hardman (1998). They recommend that parents and professionals work together to coach the student before the meeting via role-playing, videotaping, and rehearsing.

Parents should get a list of potential questions the student will be asked at the meeting. Parents may supplement this list with questions they think should be addressed. Parents can review and practice at home, and teachers can review and practice at school. Questions can include:

1. What is your best learning or working strength?
2. What skills would you like to improve?
3. What goals do you want to work on next year to help you get along better with others?
4. What vocational goals do you want to address?
5. Are there any specific school activities that you would like to participate in before, during, or after school?
6. Have you thought about what kind of job you would like to have after you leave high school?
7. Describe the lifestyle you would like to have after you leave high school (living situation, working, recreation/leisure).

We started Joey's last transition planning IEP meeting with introductions. When it was my turn to introduce myself I also said, "Joey is the captain of this team. His parents, sitting on either side of him, are the co-captains. Everything discussed during this meeting will go through Joey." (Josie Torez, Parent) [KS]

Strategies to promote student success at the IEP meeting. When students are going to participate in transition planning meetings, it is important that all team members know the students will be attending. Provisions should be made in advance to allow enough time for the conference. The meeting should progress as smoothly as possible so that students and parents receive positive reinforcement for participation and it is a meaningful process. These strategies (Berry & Hardman, 1998) will promote students' successful participation at IEP meetings:

1. Encourage the parents and students to bring a list of objectives to the meeting to ensure their points are covered.
2. Remind the parents and students that they may invite individuals who would provide support and information at the IEP meeting. Some students may want to invite a friend for moral support.
3. Encourage teachers to use nontechnical language and avoid jargon to convey information.
4. Allow the students the opportunity to ask questions; family members can assist in providing instruction on effective questioning techniques.
5. Give students the time to think and respond during the meeting and help parents be aware of how to help their son or daughter prepare for future meetings.
6. Ask students to share information relevant to transition planning.
7. Take notes and integrate the students' input. Parents can share information if the students are having difficulty articulating the information.
8. Ask for the students' opinions frequently during the meetings; prompt statements of knowledge and information taught prior to the meetings as needed.
9. Ask the students to offer feedback and react to the recommendations.

These strategies have focused on preperation for the IEP meeting. However, they can readily be applied to the Individualized Plan for Employment (IPE), as mandated by the Rehabilitation Act.

Skill Generalization Instruction

Defining Skill Generalization

Besides teaching independence and self-determination, families can provide more specific instruction that will reinforce skills learned in the classroom. Many individuals with disabilities have difficulty using skills in other settings. Skill generalization is defined as the demonstration of skills learned in one situation to a new situation among different people, using different objects or materials, in different settings, and at different times (Westling & Fox, 2000). Students with disabilities often have difficulty recalling learned material in environments other than where the skill was taught (Beirne-Smith, Ittenbach, & Patton, 1998). The more opportunities a student has to learn a skill in different settings, the more likely the student will master the skill in a variety

of settings. Because, realistically speaking, teachers cannot effectively provide instruction and practice in all settings (particularly in community-based settings), many students have trouble transfering classroom learning to authentic settings. Even practicing learned skills such as self-care, mobility, and money-handling is not as effective in artificially replicated school settings as in the environment where the student lives, works, and plays. Therefore, family instruction in the home and community is crucial. Additionally, families, as constant entities across settings and time, can be involved in skill instruction more consistently than typical school and agency programs allow. Therefore, generalization is taught most effectively with collaboration and cooperation from the student's family, the special education teacher, regular education teachers, the student, and other persons involved in transition planning.

[We work on] teaching homemaking skills at home and having him be responsible for his laundry, cleaning his room, the dog (all walks, grooming, feeding, shots, etc.), doing the house garbage and recycling weekly, mowing, shoveling, snowblower, and cooking simple meals using the stove and microwave.
(Name withheld, Parent) [MN]

Prerequisite Skills for Families to Teach Generalization Skills

Several knowledge sets are necessary for parents and other family members to be successful in generalization instruction:

1. Parents and other individuals in the student's support systems would be responsible for setting up events where the student has the opportunity to practice skills. Parents are often very well equipped for this role, because they understand their children better than others do. This will allow them to create more naturalistic, familiar settings in which to practice skills.
2. Parents must feel confident in knowing their son's or daughter's likes and dislikes and what may work and what may not to make instruction successful.
3. Parents and family members need a basic understanding of types of prompts to use to elicit skill demonstration, as well as appropriate types of materials.
4. Parents and family members must be willing to experience teaching and learning in a public places to practice community-based skills.

Challenges in Teaching Generalization Skills

Although families' involvement in real-life instruction is invaluable, some family members, as well as some practitioners, may have difficulty letting this happen. Some reasons for this include:

1. Some parents have difficulty "letting go," allowing their child to try a task with the possibility of failure. However, this does not happen solely to parents of children with disabilities; most parents have to let go at some time to their child's independence.
2. Some parents may not have the prerequisite skills necessary to foster generalization of skills.
3. Some parents may not have the time or energy to teach skills. They are likely to have work and home duties that seem to absorb their available time, and may view family-driven instruction as too time consuming and better left to the school or agency professionals.
4. Some practitioners may support the idea that instruction is the job of educators and related practitioners, and that parents and family members may be lacking in "expert" skills to deliver supplemental instruction outside the school setting.

Strategies for Facilitating Generalization Skill Instruction by Parents

Given the value of family involvement in functional skill instruction, the skills parents and siblings bring to the process, and the challenges that may accompany the implementation of this approach, several strategies for practitioners to employ are evident:

1. Practitioners should be prepared to openly discuss ways of assisting parents and other family members in this vital role; reservations and concerns need to be addressed and alleviated.
2. Practitioners should work with these parents to show them "teachable" moments, and that parents do not necessarily have to go out of their way for instruction. They should reinforce the concept of "naturalistic settings" that present themselves constantly throughout the day in the home, the store, the bank, etc.
3. Practitioners must, as needed, help families identify resources for learning materials, learn methods of generalization instruction, and practice fading of instruction as mastery is achieved.
4. Practitioners must approach family partnering in instructional delivery as a positive supplement to formal educational practices, not as a means to supplant authority or goal ownership.

No member of the transition team is expected to have all of the answers. Teaching skill generalization must be a collaborative effort with members willing to ask for assistance when needed. The major life demands of an individual may change; therefore, the essential life skills may change. The transition team must be flexible and adapt to the changes in the student's life.

Success Indicators
What would parents look like as successful Instructors?

1. Parents assist their youth in understanding their disabilities.
2. Parents support their youth's development of self-determination skills.
3. Parents work collaboratively with their youth and practitioners to develop a vision for the future consistent with the youth's preferences.
4. Parents help prepare their youth to participate fully in his or her own IEP meeting.
5. Parents support practitioners' instruction to assist in generalization of learning.
6. Parents actively use effective instruction techniques in authentic settings for independent living and community participation.
7. Parents support their youth in learning about adult settings and services so that they can be prepared to access them as independently as possible.

Conclusion

The reauthorized IDEA 1997 states that the purpose of special education is to prepare the student for employment and independent living. It is evident that school personnel alone cannot achieve this purpose. Neither can adult service practitioners successfully transition these youths into adult roles without the youth's network of support. Clearly, these outcomes are ultimately the achievement of the young adults themselves, within the support structure of family and practitioners. Together, parents and practitioners can work to improve post-school success for youth with disabilities.

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7

Parents as Systems Change Agents During Transition

Mary E. Morningstar and Josie Torrez

Parents Changing the System: Not a New Idea

Historical Context

Some of the most significant changes impacting the lives of individuals with disabilities began with parents and family members taking the role of systems change agents. Historically, parents and family members have been instrumental in major policy shifts as well as society's views about the inclusion of individuals with disabilities. The "first wave of parent activism" took place in the 1950s when parents formed key disability organizations, such as the National Association of Retarded Children (now called The Arc), United Cerebral Palsy Association, and Muscular Dystrophy Association (Powers, 1996, p. 415). During these early days, the primary role of parent organizations was to keep children with disabilities from harm especially in institutional settings, to support research, to raise money, and to advocate for educational programs for their children.

Since this time, parent disability organizations have led the way in advocating for legislative reforms, educational services for children with disabilities, and policies leading to full inclusion of individuals with disabilities into society (Cunconan-Lahr & Brotherson, 1996; Powers, 1996). It has been argued that it is often the "synchrony of stakeholders"—influential parent insiders and parent and professional advocacy groups, among others—who come together at critical junctures to effect real systems change (Turnbull & Turnbull, 1996). In fact, in 1984, Madeline Will, an influential U.S. Department of Education appointee as the Assistant to the Secretary for

the Office of Special Education and Rehabilitation Services and a parent of a son with disabilities, opened the doors for federal policies and practices that impact transition today.

The more power we can give the parents and the individuals, the better the system will work, resulting in the individuals getting the services they need. (William J. Schmidt, Director of Day Program Services) [AZ]

Diversity in Parent Advocacy

Although the first parent advocates were often those with high levels of information and resources, today's advocates include families of all races and religions. Since the 1970s, many family advocacy organizations have emerged to specifically meet the needs of diverse families with children with disabilities. Fiesta Educativa, a parent information, resource and advocacy organization for Latino families, and the Grassroots Consortium, made up of community parent resource centers for families from diverse backgrounds and neighborhoods, are two such organizations. Advocacy efforts for diverse families may include reaching out to families in family-friendly and culturally appropriate ways. Advocacy organizations may meet a family's basic needs (e.g., finding jobs, assisting with housing), as well as inform them of their rights, teach them skills, and help them negotiate complex service systems (Kalyanpur & Harry, 1999).

Systems Change Agent Defined

What exactly does it mean to be a systems change agent? Some parents are committed to advocating for their own child while others take on the whole system. In either case, systems change agents work to change systems and services for an individual with disabilities or for a representative group with disabilities. Most parents and family members don't start out trying to change systems. In fact, most only want what's best for their child with disabilities. However, because they often end up becoming such strong advocates for their children, their efforts result in changes in services, systems, policies, and practices that may impact all youth in the school district, the state, and the country. Indeed, often it takes just the power of one family wanting what's right for their child to make the most significant changes. Once parents make a difference in their child's life by being systems change agents, they discover that their child is not the only one to benefit from the change. In addition, the child with a disability witnesses what the parent is doing and learns self-advocacy skills. They watch, learn, and start putting into practice what they see their parents do to make a difference.

For parents, making a difference for their child is satisfying. In fact, many parents have attested that the time, energy, and emotional costs of fighting the system were worth it to get what they needed. All of their efforts make a difference for their child, and their job is done. For others parents, advocating for services for their child leads them to join with others and work alongside local, state, and national organizations in important systemic change efforts.

Systems Change Agents During Transition

During the transition from school to adult life, the active role of family members has proven to be an essential element to the success of students with disabilities. In many circumstances, once a student leaves school, the primary means of support, guidance, and advocacy falls to the family and the student's support network (Morningstar, Kleinhammer-Tramill, & Lattin 1999). As families and students plan for transition, they must, in fact, become advocates in ever-expanding arenas, including school, community, and agencies that offer adult services. Negotiating the maze of community services, funding streams, and eligibility requirements involves a whole new set of advocacy skills. This new arena also represents new complex systems that could benefit from parental actions as systems change agents. Parents can work to address dilemmas without being limited by current practice, policy, and what the school administration will allow. Problem solving should start with asking questions such as, "What's best for this youth?," "How can we help this youth succeed in school, the worksite, or the community?" These questions stimulate the team to collaborate and think outside the box, rather than being limited by current practice.

I have been and continue to be very vocal related to my son's transition needs. My son, although cognitively impaired, continues to learn and we have continued reading, math, and written language goals in his IEP. I also have testified about the need for care and treatment programs to have school programs reflect the "normal" school day, and am involved in a state committee to influence legislation for mental health/transition programs. (Name withheld, Parent) [MN]

Legal Requirements for Parents as Systems Change Agents

Parental involvement in systems-level decision making, program design and governance is clearly required within the regulatory language of IDEA 1997, as well as within general education reform measures, such as Goals 2000 and the recently enacted No Child Left Behind

Act (formally called the Elementary and Secondary Education Act). However, many schools, especially middle and high schools, continue to resist the idea that parental involvement on governance committees will increase students' academic achievement (Henderson & Raimondo, 2001). For parents of students with disabilities, reports of representation in school governance, site-based management and other decision-making processes reveal low levels of participation. In most instances, parents of students with disabilities and special education personnel were not involved (McLaughlin, Henderson, & Rhims, 1998).

Challenges Parents Face as Systems Change Agents

Several key challenges present themselves, regardless of the level of systems change being undertaken:

1. Negative practitioner reactions. Unfortunately, strong parental advocacy doesn't always lead to positive relationships with schools or agencies serving their children. Deborah McFadden, a former commissioner of developmental disabilities for the U.S. Department of Health and Human Services, puts it this way, "Parents know best the needs of their children. But schools will often resist their suggestions...The unfortunate truth is that if you are hated in your school system, you're probably doing a good job." (Shapiro, 1994, pg. 3). This rings true for parents who advocate during transition, as they are more likely to be perceived by professionals as difficult (McNair & Rusch, 1991; Morningstar, et al., 2001). Resistance by practitioners may stem from an overall perception that parents are not equal and respected partners. Proactive parents may trigger a defensive stance in practitioners, increasing frustration among other parents.

2. History of parent-school conflicts and mistrust. Changing this adversarial relationship can be hard, especially when parents have misjudged teachers and vice versa. Parents who had bad experiences in the past may have difficulty trusting transition practitioners. Therefore, establishing trust early is an important task for transition practitioners. Finding solutions for this dilemma is at the heart of collaborative systems change—finding ways for all stakeholders to work together as partners and create new ways to support youth as they move into adulthood.

3. Parents' time and energy. Given work and family commitments, especially when exacerbated by the presence of disability in the family, it may take an extraordinary commitment for parents to prioritize systems change activities into their lives.

4. Trepidation about how an individual can truly make a difference in the machinery of a large or cumbersome system. When faced with the daunting task of changing an established system, parents report uncertainty about advocacy roles, cultural bar-

riers, and lack of supportive environments for participation (Baker, 1997; Goldberg & Kuriloff, 1991; Hanley-Maxwell, Pogoloff, & Whitney-Thomas, 1998; USDOE, 1994).

5. Differing perceptions. Family members and educators often have differing perceptions of what is the best way for parents to be involved with school and community systems change. For example, teachers may think the best way for parents to help is by assisting their child with homework or participating in school fund-raising activities, while parents may see themselves becoming an active decision-maker for the school (Baker, 1997; Jesse, n.d.).
6. Isolation and disempowerment. As children move through the middle school years and into high school, families in general and those with adolescents with disabilities in particular, become isolated and disconnected from the school community (Gallivan-Fenlon, 1994; Catsambis & Garland, 1997). This may result in a feeling that they have no control over an unfamiliar and foreign system.

Invite school board members to the Transition IEP meetings. We found that the majority of them have never been to one of these meetings, but yet they're making decisions on special education budget and policy. At our last IEP Transition meeting, we invited the state school board member representing our community. He was glad to attend and has known Joey since he was 3 years old. He didn't give any input, but observed. Joey was glad he was there. (Josie Torrez, Parent, KS)

Strategies to Support Parents as Systems Change Agents in Transition Programming

Systems Change at the "My Child" Level

There are a number of strategies that practitioners can implement to support parents in their systems change role at the individual "my child" level:

Strengthen parent motivation and advocacy skills. Most parent advocates tell you that it takes a combination of motivation and skills to make changes happen (Turnbull & Turnbull, 2001). In fact, parents and consumers involved with Partners in Policymaking, a program

designed to help families and consumers develop personal advocacy and thereby impact disability policy development, have identified three critical skills for effective advocacy:

1. Empowering voices--learning how to communicate effectively and with whom; knowing what to say and when to say it;
2. Networking—recognizing your personal skills and characteristics and turning to family and friends for support;
3. Courage—as one participant expressed, you have to be "willing to stick your neck out for what you believe in even though people may not follow... courage is required daily" (Cunconan-Lahr & Brotherson, 1996, pg. 355).

Transition practitioners need to support family efforts to develop critical advocacy skills. School staff and adult providers can help families learn the necessary advocacy skills by offering written information, sponsoring advocacy workshops, and by connecting family members with others who are effective advocates. In fact, families often say that the most important way for them to learn about transition issues is from other families. School and adult service agencies can assist networking by, for example, sponsoring a family involvement and advocacy subcommittee of a local transition planning council. Finally, one of the most important ways professionals can support effective family advocacy is to respond appropriately and empathetically to families who are learning these skills. Professionals themselves need to understand how to communicate effectively and model these skills with families.

Help students and family members develop a vision for the future. During the transition planning process, parents may become change agents because they, along with their adolescent, possess a vision for the future that is, according to Ann Turnbull, co-director of a national family research center and a parent advocate, an "enviable lifestyle." Such a vision for the future often focuses on full inclusion in school, employment, and the community at large. In order to achieve this quality adult life, new ways to support individuals with disabilities must be developed above and beyond what schools or agencies have traditionally provided. For other parents, the vision for the future is not as clear. They may not have fully considered what their son's or daughter's adult life will be like, but they do know that the current "disability menu" available at any one agency is not what they want for their child. This may be all it takes for them to become advocates for change.

Before, during and after transition meetings, parents and students must work together to ensure that the students and their dreams are the focus of planning. Students need to have an active role and ownership in all decisions that take place during the meeting. All decisions must go through the students and relate to their ultimate lifestyle dreams before being written into their transition plans. Ownership and control over educational decision making is very important to students with disabilities, as it is to other students. We all know of students (both with and without disabilities) who do not perform as well in a subject they didn't select and don't enjoy.

To help students with disabilities achieve their goals, schools and adult agencies need to offer specially tailored planning structures. Person-centered planning is one very successful way to support families and youth in developing a meaningful vision for their futures as adults. Indeed, person-centered planning methods, which incorporate new and innovative means of support, were developed specifically to help families and individuals develop a vision for the future. The method also supports the family and individual in changing the services necessary to put this vision put into action.

Meaningful changes in services and systems can occur more quickly if parents and professionals come together to create a plan of action. For transition practitioners and adult service providers, this will involve developing a transition planning process that includes changing the way transition meetings are held to ensure first, that a vision for the future is at the core of the transition plan, and, second, that families and youth are supported in achieving this vision through services available in the school and the community. The vision for the future should not be driven by the traditional services that are currently offered. In fact, if innovative services and supports are not yet available in a community, then transition professionals must work in partnership with families and adult agencies to change the way adults are supported in the community. Keeping informed of new policies and initiatives (e.g., Ticket to Work and Work Incentives Improvement Act, Medicaid waivers, individualized funding systems, and wrap-around services) is an important role for educators and service providers. Sharing information about these new programs with families is an essential part of supporting families.

Researchers investigating how parents and consumers develop into systems change advocates have stressed that the "role of the advocate must be understood in terms of its supports and barriers, but also as a vision and passion relative to one's personal beliefs" (Cunconan-Lahr & Brotherson, 1996, p. 357). This vision and passion should be the motivating and guiding force for supporting families and youth to make the changes needed. Therefore, transition professionals must spend time with families and students to develop an understanding and respect for their personal strengths, contributions, cultural values, and how such personal characteristics impact their vision for the future.

Offer examples of quality adult lives. Practitioners who want to support parents as individual change agents offer role models and examples of how adults with disabilities similar to the child's are leading quality adult lives. This may mean educators, case managers, and other adult service staff must seek out examples of individuals helped through new and innovative services, research, policies and practices and then share this information with families.

Parents as Systems Change Agents at Local and State Levels

Outreach. Professionals can begin their support for parents' efforts by inviting them to participate in school-based and community-wide change efforts and by offering the support

needed to ensure active, meaningful, and ongoing involvement (Hanley-Maxwell, et al., 1998; Sanders, Epstein, & Connors-Tadros, 1999; Turnbull & Turnbull, 2001). Keep in mind that this participation must not be limited to disability-specific support groups.

Inviting involvement on school decision-making teams. Research has shown that it is possible to increase parental involvement at the secondary level, even with those from poor or minority families (Sanders et al., 1999). If schools encourage partnerships with parents on decision-making committees, more families will become involved in school-based activities. In fact, family attitudes and involvement in school are positively influenced by such efforts. More outreach efforts have been integrated into practices in special education and transition recently, and the initial results are encouraging. In fact, parents of youth with disabilities report that school decision-making is a critical role for them and one about which they want more information and support (Pleet, 2000).

If secondary schools are to enhance parent participation on such committees as site-based management teams, then transition professionals and secondary schools must offer parents the information and support they need to become effective partners in this role. Family involvement is more than mere attendance at school meetings or committees. Educators can facilitate family involvement during transition by: (a) asking families how they want to be involved and respecting this expressed level of involvement (b) creating comprehensive school programs that incorporate the role of families as decision-making partners (c) viewing extended family members as potential contributors, and (d) helping families and students connect with needed community services (Wehmeyer, Morningstar & Husted, 1999). When parents are involved at their initial level of comfort, they may decide to expand into other roles, including systems change agent.

Supporting parents as change agents on system reform activities. The responsibilities and burdens of gaining the knowledge and skills needed to make effective decisions in this new era of school reform and standards-based education may seem overwhelming, especially for special educators who are often not a part of the reform decision-making process. However, we are starting to see a growth in information and resources available for teachers and parents that is "usable to the extreme" (Thurlow, Elliott, & Ysseldyke, 1998, p.v). One comprehensive source for information that directly targets family members of children and youth with disabilities is Parents Engaged in Education Reform (PEER), a project of the Federation for Children with Special Needs (http://www.fcsn.org/home.htm).

It is imperative that teachers and other support personnel (e.g., social workers, transition coordinators, guidance counselors) are knowledgeable about the systems change efforts taking place in schools and that they can communicate these efforts to families of youth with disabilities. Families need general information about the intent of school-reform efforts, how standards-based reform affects their child, and how their child can master these standards. It is essential for special educators to be knowledgeable about and involved in school reform in their school and district. Families of youth with disabilities can and should be involved in this

process, particularly as members of site-based management teams. Therefore, special educators also need to advocate that families of students with disabilities be involved and included on state, district and local decision-making boards.

Involvement in district and community decision-making groups. For the most part, if parents want to impact local and community changes, they can either individually advocate for changes in services for their son or daughter or become involved in school and district advisory groups and community organizations. An excellent role for parents of youth with dis-

Partners in Policymaking: Tapping the Parent Potential

Upon graduation, partners become members of the "Giraffe Society " because they're willing to stick out their necks—Ed Roberts.

Partners in Policymaking™ was created in Minnesota by the Governor's Council on Developmental Disabilities in 1987. Partners in Policymaking is a leadership training program for adults with developmental disabilities and parents of children with disabilities. The purpose of the program is to teach best practices in disability and to teach participants how to advocate for change. Partners programs have been implemented in 46 states and 6 countries outside of the U.S. More than 8,600 Partners graduates are part of a growing international network of community leaders serving on policy making committees, commissions, and boards at local, state, and national levels.

Partners is an international training program designed to specifically train parents and individuals with disabilities together. It is an opportunity for both groups to learn together and from each other. Participants meet one weekend a month for eight months and learn from nationally known speakers about the history of services for individuals with developmental disabilities as well as state-of-art practices (e.g. community living, supported employment, inclusive education, whole-life planning). This allows advocates to develop a vision for their own personal future and for others for whom they advocating.

Partners learn about strategies for advocacy that focus on understanding how state and federal policies are formulated, how to deliver testimony for legislative hearings and meet with public officials, how to use media to promote issues, and strategies for grassroots organizing. Partners develop a strategy for advocating for a personal issue by developing specific goals, and then identifying resources and supports, barriers and opponents, and primary targets and tactics for their advocacy efforts. Upon graduating from the program, participants choose a community project to implement–one which will improve the quality of life of people with disabilities in their home communities.

A recent study of Partners in Policymaking graduates report significant changes in their lives related to housing, education, employment, case management, friendships and health care. These graduates reported that they learned critical skills for advocacy including assertiveness, communication, negotiation, leadership, networking, and how to run a meeting.

"Find out what is going on and support it or oppose it. Let your voice be heard. If we want rights, we need to exercise rights. In the meantime, do what I've been trying to do - Raise a little consciousness, raise a little hell!"

Partners in Policymaking web site: http://www.partnersinpolicymaking.com

abilities is to become active on local transition teams (Aspel, Bettis, Quinn, Test, & Wood, 1999; Halpern, Lindstrom, Benz, & Nelson, 1991). Local transition teams or councils offer a way to help communities to improve transition services for students with disabilities at the systems level. Halpern, et al (1991. pg. 1) maintain that, "The purpose of the transition council is to discover and implement new and better ways of providing secondary special education and transition services . . the essence of the transition councils . . is that they function at the local level, taking advantage of the unique strengths of their own communities while working to solve common problems."

Local councils often work together to assess, plan, and implement changes in existing services (Blalock & Benz, 1999). It is essential that parents become involved in these councils. Unfortunately this is easier said than done. Even councils that are considered to be extremely active often express difficulty in involving parents (Anderson, Lattin, & Morningstar, 2000). For example, transition councils across the state of Kansas reported that although parents were considered to be members in 88% of the councils (i.e., 23 out of 29 active councils), lack of parental involvement was often a barrier to achieving council goals.

As with other forms of community-wide change efforts, barriers to parental involvement must be addressed. Strategies for increasing parental involvement include increasing publicity and direct contact with parents to inform them of activities and events, offering food and child care, and scheduling meetings during times when families are more likely to attend.

Partnering with parents in advocating for change. Educators typically do not consider how they can and should partner with parents and consumers in advocating for changes, particularly within a school environment. Teachers and other school professionals often find it difficult to directly advocate within the system that employs them. Teachers report being told not to bring up innovative services currently unavailable in the district or risk administrative disapproval. Practitioners may have experienced the frustrations of trying to make changes from within the system to no avail.

An effective strategy for educators wanting to impact systems change is to partner with families in an advocacy role. If not directly, then indirectly by offering resources, examples of innovative programs, information about existing parental advocacy organizations and individual parent advocates who will support them in meetings and other settings, and help them network with other parents who are in advocacy roles. In this way, education and transition professionals will be supporting families to advocate for themselves, which can be a proactive and positive way to effect changes. It doesn't, however, mean shirking professional responsibilities as service providers to make a difference in the lives of students and families.

Indicators of Success What would families look like as local and state systems change agents?
1. Practitioners support parents in developing a vision for their own child's future, even when it is outside current standard practices.
2. Transition practitioners invite families to participate in school-based, local and community and state-level decision-making groups.
3. Families are provided supports to become advocates, including information, skillbuilding, connections with other families, child care for meetings, and meetings scheduled at convenient times for families.
4. Transition professionals value and encourage involvement of families of youth with disabilities on school governance committees.
5. Secondary school policies ensure that families of youth with disabilities are included in parent advisory groups and school governance committees. These policies are communicated to school staff, including special education staff, as well as all school families.
6. Transition practitioners offer a variety of options for parental involvement that are based on research-based models that have been proven to be effective.
7. Transition professionals and schools respect families who choose formal processes for advocating for changes and cooperate with such processes to avoid adversarial relationships.

Summary

Parents often describe being involved with advocacy as a life-changing event; others talk about the stress of always being the one to ask for something new. Whatever the circumstances, it is clear that without parents in the role of systems change agents, the degree of change in services and systems would not be as extensive as it is today. During the transition to adulthood, parents often are required to be systems change agents, particularly if they have a vision of an inclusive adult life for their sons and daughters with disabilities.

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JOSIE TORREZ and her husband, Gus, are the parents of two sons; the youngest, Joe, is 16 and has autism. When Joe was diagnosed, his mother learned to become his advocate to meet his needs. Becoming Joe's advocate led to a job opportunity at Families Together, Inc., the Parent Training & Information Center for Kansas. At Families Together, Ms.Torrez was the lobbyist, speaking on behalf of families' needs at the Kansas Legislature for nine years. She then went to work for the Council on Developmental Disabilities to begin a Partners in Policymaking Program as the Coordinator. She presently works for the Kansas Association of Centers for Independent Living as its lobbyist and also works on the K-PASS Grant, encouraging and training consumers on the Developmental Disability Waiver to self-direct their care.

8

Next Steps...

Donna Wandry, Amy M. Pleet, & Sharon deFur

Throughout this book, the authors have reviewed not only the various roles of parents and families in the transition process, but also the best practices that must support these roles. Guidance has been given in recognizing and valuing parents as information givers, collaborators, mentors, instructors, evaluators, and change agents within the process of helping their young adults move from school to adult life roles in a smooth and consistent manner. It has been established that parents and families, as the one constant in the lives of persons with disabilities, need to be afforded respect, sensitivity, and a prominent place in the collaborative transition process.

In addition, school- and community-based personnel affiliated with the transition planning and implementation process may need guidance and support in facilitating these active and productive roles for families. Certainly, family members must reach their own levels of comfort within varying roles, and may not consistently feel at ease being overtly involved. Despite this, or perhaps because of it, it may fall upon the practitioner to assess his or her own level of competence in the following skills: (a) assessing family members' comfort levels with the transition process, (b) ascertaining family members' willingness and preparation to move toward more proactive roles, (c) identifying his or her own potential for empowering parents to increased involvement, and (d) advocating for systemic change that will facilitate parent proactivity.

Our opinions were sought and respected. There is so much information to absorb that we appreciate how well planned and prepared the school is for helping us. (Carol Sime, Parent) [MN]

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FIGURE 1 — FAMILY EMPOWERMENT CONTINUUM ASSESSMENT AND PLANNING FRAMEWORK

	Family Characteristics	EMPOWERMENT SUPPORT ACTIONS: Share Information	Define roles and responsibilities	Provide supports and encouragement
Novice	• Family may be struggling and multi-stressed; family focus is on day to day existence and meeting basic needs; perceives personal status due to external factors beyond personal control; low feelings of power, control, or ability to change circumstances. • Perception exists that their lives and events are externally controlled. • Low skills in using resources, low self-confidence, and probable low trust of the system. May unrealistically expect that the "system" can solve the problem; dependent on the system.	• Treat family with respect and dignity • Seek to understand family culture • Identify family strengths • Identify family resources • Identify family needs • Ask family what they need to know and what they need to have immediately to improve situation • Teach family about services system(s), their rights, and responsibilities • Minimize the use of jargon • Teach family about the services available • Listen to family input about the services available • Explain how services are provided, paid for • Use a variety of means to share information • View mistakes positively	• Describe what team and families can and must do • Clearly define team and family responsibilities • Families understand that they are a member of the team making decisions about services they or their child will receive • Clarify priorities • Teach decision making skills • Teach problem solving skills and strategies • Set clear goals with families • Goal is to create a mutual understanding between families and service providers regarding problems and possible solutions or management	• Provide direct services based on families need, including immediate resources that enables the empowerment process to begin • Closely supervise process • Teach family how to access the services and resources • Provide direct problem-solving facilitation while teaching problem solving • Facilitate family decision making • Family approves the services plan • Honor family culture and values • Celebrate small as well as big successes • Communicate often to share information and to identify changes in goals
	Family Characteristics	**Share Information**	**Define roles and responsibilities**	**Provide supports and encouragement**
Emerging	• Family may be struggling, multi-stressed, or at best socially alienated. As needs are met and some success experienced, then some competence begins to emerge, while confidence and trust may be variable. Families may be easily discouraged at this stage as changes may be inconsistent with expectations. Goal is to begin to develop a sense of personal self-efficacy leading to increased commitment.	• Use information to align expectations with reality • Identify the impact of actions that the family initiated or approved • Share information to build confidence and pride in accomplishments • Listen reflectively to family messages • Share positive and negative information • Praise families for identifying problems • Expect tough questions • Share information about social networks	• Revisit goals collaboratively • Teach goal setting • Set skill goals as well as service goals • Focus on continuous growth • Teach families how to advocate for themselves • Broaden scope of decisions to be made by the family • Help develop adaptive capabilities and competencies • Teach coping strategies	• Continue to provide direct service and supports • Coach family in accessing and advocating for services within the community • Emphasize developing relationships with the family and among family supports • Link with other families and social supports • Identify family mentor as appropriate • Celebrate, affirm, and give family ownership of successes • Focus on increasing competence, confidence, and commitment
Empowered	• As families experience success and integration of skills, their competence and confidence increases. Goal of empowerment is family self-reliance and at this stage families ability to set and act on goals increases. Able to use and identify resources to solve problems. Responsibility for the outcomes can be assumed by the family, or minimally shared with the system. Trust in self and in the system improves. Family moves toward independence or interdependence.	• Continue to share all relevant information • Respond to families inquiries for information • Praise families and each other for sharing information • Share mistakes too, and problem solve how to use those to improve future actions • Use information to check team and family accountability	• Encourage families to monitor and report on progress toward meeting goals and the impact of services • Revisit goals to ensure maintenance and generalization of new skills and confidence • Assist families in setting own goals • Encourage families to take on role of mentor to other families, as appropriate	• Continue direct services as requested and appropriate. • Encourage families to identify and access services on their own. • Ask families to provide feedback to the system regarding the services providing and the processes followed • Identify and develop a follow-along support and services plan
	Empowered families recognize those events that are within their control. They are able to reframe problems and redefine goals as appropriate to their circumstances. They seek creative solutions, take action, or employ appropriate coping strategies. Their well-being is enhanced and capabilities are strengthened.			

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Assessing Family Empowerment

As stated throughout this book, families experience their own levels of comfort and report varying degrees of partnership in working with professionals. Families' collaborative relationships with professionals can be affected by past frustrations in not being listened to and heard, low self-confidence in interacting with "experts," learned dependence on an overwhelming system, lack of knowledge about resources and rights, and ongoing stressors linked to the presence of disability in the family. Practitioners must step forward to identify the family's level of receptivity to collaboration, and to recognize the continuum through which families may pass as they strive to become more empowered. Figure 1 identifies three different levels of an empowerment continuum. Within each stage, family characteristics are described relative to their interactions with the larger system. These descriptors may be used to help practitioners assess families' readiness to be proactive within transition planning or any other systemic activity that requires collaboration (such as program evaluation or student assessment). Practitioners can use the empowerment support actions, offered in each stage, to assist families in moving toward the next stage of the continuum, or, at least, support them in the stage in which they are comfortable.

We had a chance to think about her transition for many years before our daughter's graduation, so we had time to make sure all necessary services were in place. Our daughter's IEP team lead also made sure our daughter had lots of practice using self-advocacy skills, which made our job easier. (Charlsie Armstrong, Parent) [MN]

Fostering Family Empowerment: Practitioner Self-Assessment

Equally important to determining family readiness to assume collaborative, proactive roles is the need for the practitioner to determine his or her own openness to increased family involvement and the potential for creating and fostering increased involvement. Parents and other family members, even if they seek their own empowerment and create their own goals for interacting with a system, cannot be successful if the professionals with whom they work are not receptive to their proactivity. Therefore, in addition to determining the readiness level of family members to become information-givers, collaborators, mentors, instructors, evaluators, and change agents, an effective practitioner will seek to critique his or her own attitudes and actions that support or hinder family empowerment within those roles. Figure 2 presents a self-rating scale that allows practitioners to evaluate their own actions toward family members during the

FIGURE 2—COLLABORATIVE PARTNERSHIP SELF-ASSESSMENT—SERVICE PROVIDER FORMAT

	Always	Usually	Sometimes	Seldom
1. I put myself in the family's place to consider how I would feel as the family of the youth or young adult with a disability.	4	3	2	1
2. I believe that the family members are equal to me as a professional and, in fact, are experts on their son or daughter with a disability.	4	3	2	1
3. I value the comments and insights of the family and make use of their knowledge about the needs of the youth or young adult with a disability.	4	3	2	1
4. I listen attentively to the family, communicating with words, eye contact, and posture that I respect what they have to say.	4	3	2	1
5. I create an environment in which families are comfortable enough to speak and interact.	4	3	2	1
6. I avoid the use of jargon in my conversations.	4	3	2	1
7. I tell families about other resource families who have experienced the "transition process" and assist in the development of family networks.	4	3	2	1
8. I share information with families about how the special education and adult service system works, other available resources, and other service providers.	4	3	2	1
9. I work with families to identify family strengths and to use these strengths to build competence and confidence in their role as transition case managers.	4	3	2	1
10. I create opportunities to celebrate successes and provide ongoing encouragement to families and youths regarding transition outcomes.	4	3	2	1
11. I know about, and understand, the cultural backgrounds of the families with whom I work.	4	3	2	1
12. I work with families to set goals that are specific, motivational, attainable, relevant, and trackable.	4	3	2	1
13. I connect families to community transition resources, including other families.	4	3	2	1
14. I teach families skills to develop competence about the service system, problem solving, and advocacy.	4	3	2	1
15. I treat families as team members engaged in problem solving regarding their youth or young adult with a disability and learn from them.	4	3	2	1
16. I ask families to provide feedback to me about our communications and other interactions and their interactions with the service system.	4	3	2	1
17. I try not to do something for families when they can do it themselves.	4	3	2	1
18. I avoid speaking for families or solving problems without involving them in the process.	4	3	2	1
19. I respond to families with respect and personal relationships rather than bureaucratically.	4	3	2	1
20. I am aware of my own ethnocentricity and of the external triggers that might prejudice my respect for the culture of the families with whom I work.	4	3	2	1
21. I help plan services and supports that tap into the family's strengths.	4	3	2	1
22. I listen to the family's requests and help them take on the primary decision-making role in planning transition services for them and their youth or young adult with a disability.	4	3	2	1
23. I believe that families know what they want and need.	4	3	2	1
24. I believe that families have the capacity for parental growth and development.	4	3	2	1
25. I believe and act upon the establishment of parent-professional partnerships, shared decision-making, and mutual respect.	4	3	2	1

HOW DO YOU RATE?

Total your ratings for all items. Divide this number by 100 to get your percentage score.

90%+ = Outstanding — Help your teammates develop these knowledge, skills, and attitudes!

80%+ = Above average — Review your ratings and make sure there aren't any glaring areas; continue to grow and develop.

70% = Average — There are probably some areas that could use attention.

Below 70% = Below average and problematic to creating an environment conducive to partnering with families. Decide where your strengths are and use them to promote family empowerment. Check out the major holes and develop an action plan to improve. Take this assessment again in 2 months.

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transition planning and implementation process. It provides practitioners with the opportunity to critically review their own beliefs, values, and professional practices. The scoring mechanism indicates where efforts may need to be directed to increase overall effectiveness in creating a positive, supportive environment where families can develop competence and confidence.

Calling for Leadership in Systemic Change

Local School or Agency Level

Anyone who has worked within an educational or related service system is aware that the best growth occurs, and the most innovative programs can take root, when administrators are supportive. Therefore, a next-step discussion must include what administrators within school and agency settings can do to encourage practitioner development of strong collaborative relationships with families, as well as family empowerment within their organizations. Suggestions for greater practitioner collaboration inevitably carry an underlying assumption that these individuals have the available time, resources, and programmatic control to effectively fulfill this role, and that failure to do so is indicative of a lack of will or desire (Fox, Wandry, Pruitt, & Anderson, 1998). Most suggestions offered throughout this book demand no more than a rethinking of attitude and approach. However, some of the suggestions may require a realignment of work activities to provide professional development opportunities, create parent-friendly processes and products, etc. The key, then, is to recognize the role of the administrator in encouraging the less overt practitioner activities and supporting the more overt ones. Indicators for success for administrators may include:

1. School or program goals and corresponding staff division of labor is realigned to include dedicated, formalized outreach activities to parents and families.
2. Adequate resources for parent outreach and support (newsletter printing, parent groups, etc.) are designated.
3. Adequate staff training is arranged with parents and families as active participants in content delivery and discussion facilitation.
4. Staff members are aware that respectful interactions with families are the responsibility of all.
5. Staff members are recognized for effective practices that build partnerships with families.

It has been very challenging to make parents aware of our services and to what extent we can provide some services. Once partnership is established, parents feel more comfortable and become more of an asset in empowering their young adults to be self advocates. (Name withheld, Senior Rehabilitation Specialist) [FL]

National and State Levels

Just as the individual practitioner may be hampered by lack of administrative support, local schools and agency organizations are affected by state and national mandates and implementation regulations. Therefore, a final point in the next-steps discussion must include what, besides promising language, state and national leadership can do to facilitate family involvement and leadership in the transition process.

A more global representation of specific mandates designed to educational systems is found in the current administration's No Child Left Behind Act. This policy reflects the need to operationalize parental choice, school improvement, and teacher quality. Specifically, the policy stresses the following priorities, with accompanying rewards and sanctions:

1. Maintaining accountability and high standards.
2. Providing consequences for schools that fail to educate disadvantaged students.
3. Improving literacy by putting reading first.
4. Expanding flexibility and reducing bureaucracy.
5. Rewarding success and sanctioning failure.
6. Promoting informed parental choice.
7. Improving teacher quality.
8. Making schools safer for the 21st century

Although the bold actions outlined within each of these areas are not specific to transition, certainly many of them can be interpreted as a foundation for improving school-to-adult life services for students with disabilities. Specifically, efforts should be made at federal and state levels to mandate, support, and tangibly reward the following conduits to improved, more collaboratively designed and delivered services that support family participation:

1. Accountability and high standards for post-school outcomes reflecting successful movement into adult roles that reflect true person-centered planning.
2. Decreased bureaucracy involved in movement among and between schools and adult services, including consumer-friendly funding venues and eligibility requirements that facilitate collaborative decision-making, planning, and program evaluation.
3. Innovative transition practices that can be replicated and systematized beyond short-term seed funding, and therefore sustain established partnerships.
4. Models of creative collaboration with families that include true practitioner incentives and time/resource allocation.
5. Family training venues that contribute to informed parent and consumer choice-making and advocacy.
6. Teacher training programs that adhere to professional competencies addressing collaborative partnerships with families and other practitioners.
7. Innovative creation of incentives for local districts to hire designated transition specialists skilled in collaborative practices.

Final Words

We have a dream. We dream of a world in which parents and practitioners work together as partners to support and empower youth with disabilities to develop their potential to the fullest. In this dream, practitioners value and support diverse parents and families as partners in planning, instruction, evaluation, and systems change activities. Practitioners build on the possibility of working as team members rather than competitors. Parents are confident that practitioners are working with them and do not have to threaten legal action to be heard. Practitioners grow in their sensitivity to home-based issues impacting their students and clients on a daily basis. Practitioners continually assess their own actions and values in the process of critically improving their professionalism. Parents and practitioners are always willing to be simultaneous leaders and followers in the collaborative process. Ultimately, parents and practitioners revel in shared communication and celebrate the successes they have collaboratively fostered in young adults' achievements.

Council for Exceptional Children

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